# Using Writing as a Therapy for Eating Disorders: The Diary Healer and the process of using personal diary excerpts to write a book to assist people with eating disorders

Thesis submitted in fulfilment of the requirement of the degree of

PhD in Creative Writing

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# Certificate of Authorship and Originality of Exegesis

The work contained in this exegesis has not previously been submitted either in whole or in part for a degree at CQUniversity, or any other tertiary institution. To the best of my knowledge and belief, the material presented in this exegesis is original except where due reference is made in the text.



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## Notes on Reading this Thesis

I wish to explain that the creative work written as part of this thesis has been published.

Routledge (London) released the creative work, titled *Using writing as a therapy for eating disorders—The diary healer,* in July 2016. What is included here is the book manuscript submitted to Routledge in January 2016. Although amendments to the original manuscript prior to publication were minor, these have not been included in this manuscript, so as not to confuse what was my work, and what was suggested or contributed by Routledge. A copy of the published book is available.

Some repetition, for example on the reason for this research and the processes involved in sourcing participants and creating the book, has been necessary in the creative work and exegesis due to an embargo on the creative work as a result of this publication. Such repetition makes possible the desire to release the exegesis for digital theses repository deposition.

#### **References**—Authors with Same Surname

The APA referencing style is used throughout this thesis. While it is usual for initials to appear after the surname, you will notice that several citations in the text appear with the initial before the surname. This is because, when a reference list includes publications by two or more primary authors with the same surname, the APA referencing style is to include the first author's initials in all text citations, even if the year of publication differs. (See http://blog.apastyle.org/apastyle/2014/01/when-to-

v

use-author-initials-for-text-citations.html and Publication Manual of the American

Psychological Association (APA) 6th Edition 6.14, p. 176.)

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# Background: My Diary, My Illness and Me

#### About Me

The story behind this research project begins in 1962 when, at age 11, I developed an eating disorder and began to keep a diary. The themes and threads that bind the story together, however, began to weave a pattern almost as soon as I was born. In early childhood, the world through my eyes comprised a small, beautiful valley adjoining the Mitchell River National Park in Victoria, Australia. I lived on a dairy farm with my parents and sister. For my first 11 years, my home had no electricity, television or Internet, but my days were full. The farm, river and adjacent bushland provided a natural outdoors playground, seeding my imagination. Indoors, on rainy days and at night by lantern-light, at the solid oak kitchen table, I would ask my mother for pen and paper and write a note or two about my day. A friendship with words was already taking hold.

When my formal education began at age five, my world began to expand. A bicycle ride two-and-a-half miles along a gravel lane out of the valley led to a sturdy, one room, one-teacher, 20-pupil school. Here, my love of words intensified and the happiest days were when new books arrived for the school's small library. At age nine, a prize of a pen in a national story-writing competition fuelled my writing passion, and broadened my horizons. I learnt that if I wrote well, acknowledgement might follow. Soon my stories, based on observations of adventurous wombats and other aspects of my daily life, were appearing in publications like the Sydney-based *The Australian Children's Newspaper*.

Both my parents had left school at the age of 14, to milk cows on neighbouring farms. I never saw either of them reading a book. My mother wrote letters to family and friends, and my father read newspapers, but this was the only evidence of the written word in our family home. I did not have opportunity to visit a municipal library until I began secondary school at age 12. To their credit, however, my parents tolerated my literary interest and provided pens, writing pads and stamps. Pen-friendships in far off lands, including the United States and Germany, letters and articles to newspapers, and essay competitions provided other outlets for expressive writing as I entered adolescence. Words were my friends because they were safe, accommodating, did not judge and did anything I wanted them to.

Early in 1962, the year before I began secondary school, my world changed. The teacher's announcement of an impending school doctor visit worried me. I felt terrified about undressing for what was a routine medical test in the vicinity of my teacher, a male cousin who boarded with us.

My mother and sister were dismissive when I expressed concern, and my anxiety intensified to the point where one day, while sitting alone on the grassy school ground bordered by tall pine trees, my tension suddenly eased. Anorexia nervosa was developing and providing me with a coping skill. With each new day, I progressively ate less and exercised more. In this way, my fears were suppressed as my focus moved from worrying about the doctor's visit to calculating what I could eat and how many hours I needed to exercise each day. Several months later, the school doctor came and went,

but my terror of eating remained, for the process of disconnection of my identity from body had begun.

I did not understand why I was afraid to eat, or why I could not sit still. My frustrated mother criticised my behaviour and compounded my guilt. I retreated and became withdrawn. Then, the gift of a diary at Christmas provided a reprieve. I now had somewhere to off-load and store the calorie numbers and food and exercise rules that were cluttering and dominating my mind. The pen and paper provided an external connection, a tangible recording tool. Until now, the eating disorder thoughts had been internalised but the diary offered a private place to externalise them as well; the mere act of writing the figures and words on the page allowed a sense of control and easing of anxiety, however brief. In this way the diary, like the eating disorder, became a coping mechanism for meeting the demands of daily life. Becoming what seemed an immediate, trusted friend, the first little book marked the start of a literary journey that, over the next 40-plus years, would chronicle the loss and recovery of identity and self.

# About My Diary

Just one word described how I felt about my first diary. Excitement. The entry for January 1, 1963, is crammed with details of food consumed, exercise taken, the time of awakening and going to bed, and the cricket results. Other entries in this first year of diary-writing include matter-of-fact mention of friends and family and observations including the weather, the start of secondary school education in seventh grade, my father's seasonal farming activities, the number of hen eggs collected, and the days in the week when I bathe or wash my hair. By the end of 1963, when I transitioned into

full-blown anorexia-bulimia, more self-expression is evident. In adolescence, words tumble out, trying to make sense of thoughts and feelings, and the limitation of one page a day is sometimes a challenge—my handwriting gets smaller and smaller as the end of the page approaches. My world is small. There is the diary, and me. Not for many years would I learn there was also the eating disorder, and that the diary's influence extended far beyond the two of us.

The illness, like the diary, thrived on privacy and encouraged the keeping of secrets. As a child and young woman, my diaries were safe places in which to express and analyse thoughts, and develop coping strategies. But confiding in the diary also strengthened the eating disorder, its unrelenting and stringent demands becoming increasingly impossible to meet. Nothing I did was enough and the rules of the illness became secrets within secrets that had to be guarded and hidden from others. By age 28, my diary had recorded an almost complete disconnection of self from body.

Outwardly, I presented as a wife and mother with a full-time career but within, the diary revealed a desperate struggle to honour daily lists and pledges, for instance, having a strict weight limit, running a set distance, and noting every calorie. Thoughts of suicide after 17 years with the disorder drove me to break the silence, and reveal the thoughts hitherto confined to my diaries, to a doctor. He and other doctors, upon learning I kept a diary, encouraged the continuance of such writing as a tool for expression. However, like me, they were ignorant of the diary's potential to play a pivotal role in my illness, and of its ability to be a foe as well as friend. Eventually, in my 30s, a psychiatrist gained my trust and suggested I could use the diary to assist the

healing process by drawing on it in engaging in written communication with him. Gradually, aided by patient, therapeutic guidance, what I wrote in my diary began to reconnect with my thoughts and feelings. Self-abuse and self-harm gave way to self-care as my body and mind progressively reintegrated. Decades later, at age 55, upon healing sufficiently to re-enter life's mainstream, I departed a journalism career to reflect on these decades of diary-writing and write a memoir.

As I 'came out' and began to share my story publicly, the diaries 'came out' too. For instance, besides providing the main data source for my memoir, *A girl called Tim* (2011), they became a resource pool of documented 'lived experience', assisting the dissemination of science-based knowledge and evidence-based treatments in books for health professionals and mainstream readers. In another outcome, the creation of a website as a companion to the memoir led to people with experience of eating disorders writing to say they had 'connected' with my story in a way that gave them 'permission' to share their stories until now revealed only, if at all, in their diary. Many adult readers wrote at length, explaining they had felt isolated and had kept their eating disorders a secret for decades, but upon reading and identifying with my story, were able to share and externalise their thoughts and experiences for the first time.

Reflecting on the reader responses sparked recognition that perhaps my friend the diary had been destructive as well as constructive throughout my long illness. This revelation in turn became the catalyst for this research project, investigating how diary entries might be used in writing a book exploring how the process of diary-writing can be a tool for self-healing and renewal.

# Introduction

In January 2014, I set out on a literary journey with more than 70 strangers. They had responded to an invitation I posted in an Internet blog, asking if diarists with experience of an eating disorder would like to participate in a book. I had met none of them face-toface and was unaware of their ages or countries of origin. Over the ensuing 30 months, my work with these diarists would form the basis for this doctoral submission, investigating how diary entries can be used to write a book. The book, as a creative work, explores diary-writing as a recording, healing and therapeutic tool, while the accompanying exegesis seeks to drill down to examine the essence of the diary genre and how it could be used to write a book. This process would involve drawing on, and reviewing, the layers of interaction between each of the 70 diarists and myself, the threads that bound us and, furthermore, the techniques involved in utilising this material as a source and foundation for literary endeavour. The creative work, a book titled Using writing as a therapy for eating disorders: The diary healer (working title, used hereafter: *The diary healer*) has been the outcome, exemplifying this approach. Routledge published this work in July 2016.

*The diary healer* integrates the voices and experiences of the 70 respondents with my own, exploring the role and use of diary-writing as a coping, survival and healing tool. The exegesis, in describing the process of creating *The diary healer*, also seeks to define the diary as a genre of writing, and investigate the use of the diary not

only in literature, research, health and education, but also in the everyday lives of the individuals who have kept or keep a diary.

The preceding Background Chapter describes the sequence of events inspiring my quest to discover whether diary entries could be used to write a book exploring how diary-writing could be a tool for self-healing and renewal. Preparation for this literary mission required transitioning more fully from the practice of being a diarist to being an observer of my diaries and, subsequently, also the diaries of others. In standing back and looking in, I was shocked to discover the extent to which the diary had been an accomplice of my own illness. The two had been in collusion over many years. Yet, despite this deceit, diary-writing had helped me to function, and survive, during decades of chronic mental illness. Moreover, with the right therapeutic intervention, the diary had helped me to re-connect with, and reconstruct, a long-suppressed identity that was not engaged in self-delusion. My diaries had helped me to develop the ability and skills to live a full, rather than part, life. But did my healing journey have to be so long and tortuous? How much did the diary help and how much did it hinder my recovery? Could the diary have provided a more pro-active role in healing? I wanted to find out.

Writing a memoir (Alexander, 2011) had helped to place the illness in the context of my life and to relate with others. Now I wanted to learn about the diary's usefulness more widely, and explore its status as a literary genre. An investigation of its role in mental health care environments ensued, with a focus in the specific area of eating disorders revealing scant reference in the literature on the effect of diary-writing.

As well, there was a dearth of evidence-based literature on the diary's influence during the process of disconnection and re-connection between body and identity. These findings, alongside other aspects of the diary and diary-writing, are explored in Chapter One (Literature Review).

Reflection on these discoveries inspired the concept for the manuscript that became *Using writing as a therapy for eating disorders—The diary healer* (2016). I wanted to explain the pitfalls and benefits of diary-writing and, specifically, to explore the ambivalent relationship with body and identity that could occur when experiencing an eating disorder. Furthermore, I wanted to study the role of the diary in self-healing and renewal, with the intention of combining and presenting the findings in a creative way that would stimulate reader interest.

Consideration of submissions, from diarists who had responded to my blog invitation, gave rise to telling the story from two viewpoints—that of diarists, and of scholars. The approach I had in mind would allow, I hoped, both myself and other people with experience of eating disorders to 'speak' through the written narratives of our private diaries in this project, contextualising this alongside evidence from researchers. I also wanted to explore this technique's effectiveness in creating a text that could offer fresh perspectives on the diary's potential to motivate and assist healing.

My decision to take this approach stemmed from my personal experience combined with evidence from experts and scholars in the fields of psychiatry and literature. The information gathered indicated that when a person develops an eating disorder, symptoms manifest around food and often lead to a disconnection between

body and identity (Dayal, Weaver, & Domene, 2015). The person is driven to engage in acts of bodily self-harm rather than self-love (Hodge & Simpson, 2016). Besides disconnecting the person from their sense of identity, the illness often causes the person to become disconnected from close others, including family and friends (Curry & Ray, 2010); Dayal et al. (2015); (Tantillo, 2006)). My diaries had provided a safe repository for confused feelings and thoughts that could not be shared with others during my own experience of such disconnection (Alexander, 2011). I wanted to know more about this but the Literature Review revealed a lack of evidence-based writings in this area. This deficit of research on keeping a diary was occurring at a time when healthcare in general is increasingly focused on evidence-based practice (Haigh & Hardy, 2011; Hurwitz, 2000) and patient narratives are gaining recognition as an effective educational tool (Haigh & Hardy, 2011; Woesner & Kidd, 2013), a method for understanding illness and improving healthcare (Hurwitz, 2000; Hurwitz & Charon, 2013; Shapiro, 2011), and for addressing healthcare provider-based stigma (Charles, 2013), illness-based self-stigma (Patrick Corrigan, Kosyluk, & Rüsch, 2013) and stigma in the wider community (Patrick Corrigan, Larson, & Michaels, 2015). I aimed therefore, for this project to provide research into diary-keeping through the lens of diarists with an eating disorder, and present possibilities for application of the diary in investigative, therapeutic and self-help ways.

A major challenge in the successful treatment of eating disorders is the patient's reluctance and resistance to change (Kaye, 2008; Touyz, Le Grange, Hay, & Lacey, 2016; Vitousek, Watson, & Wilson, 1998; Zaitsoff, Pullmer, Cyr, & Aime, 2015). Recovery starts

only when the patient experiences insight, termed a turning point or tipping point (Dawson, Rhodes, & Touyz, 2014a) that motivates recovery and enables the patient to understand they are ill (Hay & Cho, 2013; Hipple Walters, Adams, Broer, & Bal, 2015). More research is required to understand the complex multiple ways that may lead to a tipping point (Hay & Cho, 2013). When recovery does commence, the first step, beyond and besides intake of adequate nutrition, is for the patient to start moving away from an identity that their eating disorder has defined for them by re-establishing a connection with their own identity and complex sense of self (Cruzat-Mandich, Díaz-Castrillón, Escobar-Koch, & Simpson, 2015). The development and retaining of a sense of autonomy and choice (Vandereycken & Vansteenkiste, 2009) can help sustain this process. This exegesis, therefore, explores the use of the diary in the process of disconnection and re-connection of self as portrayed in my creative work, *The diary healer*.

Selected excerpts from diarist participants, together with evidence-based insights from researchers and therapists, are integrated in this book to present new possibilities in a field which reveals a) a paucity of empirical findings on causes and b) a dearth of consensus on solutions for recovery (Dawson, Rhodes, & Touyz, 2014b; Noordenbos, 2011a, 2011b). *The diary healer* illustrates how the diary, an oftenmaligned literary form (Lejeune, 2009; Maunsell, 2011; McNeill, 2010), can be used creatively to produce an innovative, non-fiction narrative work and contribute to answering the research question:

How can diary excerpts be used in writing a book to assist people with eating disorders?

The diary healer presents diarist evidence in a way that I hope encourages the reader to reflect and reach his or her own conclusions. The mapping of the approach to the research and the thought processes and decision-making strategies employed in creating the book's concept, structure and content, are explored more deeply in this exegesis.

Within the book itself, the Preamble (pp. xxi–xxv) helps to prepare the reader to embark (with the diarists) on a self-discovery path. Threads of first person narrative weave through 25 chapters divided into two sections—'Writing for Self', and 'Writing for Therapy'. Threads in the first section reveal inside stories on choosing a diary, creating a friend, secrets, abuse, reflecting and connecting with self, learning about self through the stories of others, stigma, early illness signs and symptoms, recovery and how the diary helps in moving on. The second section looks at the diary as a 'connector'—that is, in facilitating communication between the patient and their therapist—and explores poetry, trust, relationships, forms of diary-keeping and sharing, behavioural health technology, creating a narrative for others, and being a participant in, and observer of, one's own life. In both sections, insights from health practitioners and researchers are used to support this other content.

This exegesis also examines the reasons behind the decision to present the narrative primarily through the patient's voice. The content of diarist extracts, for instance, supports studies indicating that, to improve eating disorder treatment and

recovery regimes, social and interpersonal perspectives in care provision merit consideration (Cardi et al., 2015; Hipple Walters et al., 2015; Vandereycken, 2006). Another message I attempt to relay through the diarists is that addressing a person's level of motivation and readiness for change in a recovery-based model (Dawson et al., 2014b) through narrative means such as the diary may be beneficial in countering high rates of dropout and relapse (Dawson et al., 2014b). Personal narratives, it also is shown, can provide valuable reflective opportunities and fresh insights, and assist not only patients but also healthcare professionals and caregivers in learning about themselves, the effectiveness of therapies and treatments, the illness and any underlying problems (Bolton, 1999a, 2010; Hamilton, 2012; C. Jones, Bäckman, & Griffiths, 2012; K. A. Jones, 2012; McAllister et al., 2009; Ong & Jinks, 2006; Perier et al., 2013; Pert, 2013).

In Chapter One, the 'Literature Review' reveals how the process of creating *The diary healer* (2016), besides providing fresh perspectives on the diary as a literary genre and healing tool, unearthed gaps in the relevant literature.

In Chapter Two, 'Methodology', I explore how creative practice-led research methods can integrate reflective and independent thinking with a patient-based approach. This, together with the analysis and evaluation of material sourced through the Literature Review and my research participants (which is what the other diarists became) enabled the project's outcomes to be delivered. Diary extracts comprised a major data source for this non-fictional work, which, while drawing on the diary's history and its roles in the English-speaking world, primarily focuses on themes of diarywriting for purposes of self-healing and renewal. Creative practice-led research came to

the fore in the selection of diary excerpts for *The diary healer*, and their incorporation into a text to allow the issues surrounding body and identity to be explored and, hopefully, to stimulate the book's reader to engage with the material presented.

My literature review found that authors have few examples on which to base a non-fiction work including diary extracts should they desire to include them in their texts as a narrative component. Through the investigation of diary-based research, pertaining to the traditional pen and paper diary and, more recently, the on-line diary, with a particular focus on diarists with experience of an eating disorder, the exegesis demonstrates how practice-led research techniques help to facilitate the interpretation, structuring and composition of text to support *The diary healer* narrative. The distinguishing events and influences affecting diaries, particularly since the 1600s, are identified and drawn upon to inform and underpin the themes, narrative construction and literary devices chosen to develop and produce the book.

Chapter Three, 'Process', explores the process developed to write the book using the creative practice-led research method. Elements include the concept development, information sourcing, and text structure. Unexpected outcomes are noted as, for example, how two new chapters, on poetry and secrets, were created as a result of revelations in diarist submissions and an early chapter on the history of diary-writing was deleted. Methods employed in traditional diary-writing and through the diarywriting elements of social media tools (Aardoom, Dingemans, Boogaard, & Van Furth, 2014; Hipple Walters et al., 2015; Tregarthen, Lock, & Darcy, 2015) are examined in order to gain insight into the usefulness of this medium in engaging with individuals with

eating disorders, many of whom, Tregarthen et al. (2015) reveals, are not receiving clinical treatment for their illness. Strategies for selecting excerpts and quotes for inclusion in the book are outlined, for example, the process of selecting excerpts from the submissions, which totalled in excess of 300 000 words, and deciding how to integrate them in a book length manuscript. Likewise, there is a discussion of the process of selecting first person excerpts, and deciding when to quote or paraphrase, when to draw on evidence-based research to support the patient's voice, and when to illustrate that intervention with therapeutic guidance might influence the outcome (Cardi et al., 2015; Gamber, Lane-Loney, & Levine, 2013; S. P. Jones et al., 2014; Pennebaker, 1997b; Pennebaker & Seagal, 1999). Factors leading to diarist participation in the creative work are explored, at the forefront of which is the establishment and maintenance of trust.

Chapter Four, 'Insights', includes discussion of the challenges and process in creating a book about the diary on a subject that is suitable for, and appealing to, mainstream readers, while meeting the standards required in a scholarly publication. An example of this is the effectiveness of diary extracts as a voice in enhancing the narrative. The interplay of these different voices, between thoughts, feelings and behaviours (the 'setting') contribute to role evolution (the 'character development') and story thread (the 'plot').

The 'Conclusion' draws together the main elements and outcomes of the research, reflects on the publication of the creative work, and discusses options for building on the findings with further projects and research.

In summary, the widespread narrative sharing among diarists that followed the release of my memoir, *A girl called Tim* (2011), sparked a yearning to study the role of diary-writing in healing from trauma and illness and became the catalyst for this research project. This thesis, comprising the creative work *The diary healer*, published in 2016, and this exegesis, explores the process and challenges associated with writing a non-fictional book based on diary excerpts.

The Exegesis

# Chapter One: Literature Review

# Introduction

Through its focus on the process of using personal excerpts to write a book to assist people with eating disorders, this exegesis provides insight on a subject that, this literature review reveals, has often been overlooked in the research field. The aim of this literature review is to establish a foundation to assist in exploring my research question: *How can diary excerpts be used in writing a book to assist people with eating disorders*? Accordingly, this review explores the history of the diary, how diaries have been used to help people, eating disorders, and the diary's relevance to people with eating disorders. The review also looks at what is known about recovery from mental illness, and the role of lived experience, particularly in the treatment of eating disorders.

While concepts of 'diary' and 'journal' each refer to the keeping of a daily record of experiences, for consistency this review is limited to the word 'diary' and within the bounds of English speaking works within the past 100 years. This thematic review also is confined to diaries that pertain to personal use, the health field and their application, and are relevant to diary-writing as a life writing, literary genre. The literature review revealed much on the history and development of the diary in many scholarly fields of endeavour. However, while interesting, most such works are deemed outside the focus of this exegesis. (For more about the history and development of the diary, refer to Alexander, Brien et al., (2015)).

#### Data Collection Method and Organisation for this Review

Scholarly material for this literature review has been sourced primarily and almost exclusively by trawling the Internet, conducting database searches, on-line searches of library collections, as well as in-person library searches. Often an accumulative effect occurred, with one search unearthing a fresh lead, which in turn revealed another, and another. Databases accessed included: Cinahl, Cochrane Library, DiscoverIt!, Ebscohost, Emerald, Google Scholar, PsycARTICLES, Psychology and Behavioral Sciences Collection, Psychology Collection, PsychINFO, PubMed, PubMed Central, Medline, SAGE Journals On-line, Springer Journals On-line, Taylor and Francis On-line Journals. Boundaries were established to include only English papers that were peer reviewed, and published between the years 1920 and 2016. Key search terms included: 'diary', 'solicited', 'unsolicited', 'journal', 'blog', 'personal narratives', 'letters', 'writing', 'stories', 'private document', 'eating disorder', 'body', 'mind', 'identity', 'authenticity', 'self', 'eating disorders', 'anorexia', 'bulimia', 'BED', 'mental illness', 'health service', 'therapy/therapeutic'.

Creation of an Endnote Library expanded expeditiously to 1472 papers. Papers were progressively collated and placed on to 15 labelled shelves. Shelf labels included: 'self', 'books' (historical/literature), 'diaries', 'eating disorders', 'education', 'healthcare', 'memoirs/story-telling', 'narrative medicine', 'writing tasks', 'methodologies', and 'poetry'. Each shelf contained numerous sub-shelves. The 'diaries' shelf, for instance, included sub-shelves for 'healthcare', 'noted diarists', 'evolving definition/use', 'intensive care', 'memory', 'on-line versus face-to-face therapy', 'on-line blog',

'participant research', 'patient reported outcomes', 'professional personal benefit', 'solicited', 'suffering narratives', 'unsolicited', 'apps/smartphone', 'paper compared with on-line and SMS', 'patient/therapeutic recovery' and 'palliative care'.

### The Diary as a Literary Genre

Non-solicited and pre-existing diaries have a long tradition, especially in literary terms (Serfaty, 2004). Lejeune's work (2009) on diaries has become seminal in the field and led to intensified interest in (non-solicited) diaries and diary-writers in the 1980s. Lejeune dedicated much of his research to privately written, unpublished diaries and to the questions of where the diary comes from and why people keep diaries. Lejeune (2009) also traced the diary's origin and posited that the initial purposes of keeping a diary related to commerce and organising one's work life; however, in time, it transformed to a means for the individual to monitor a spiritual relationship with God and then, from the late eighteenth century, to a more dialogue-based, intimate relationship between the diarist and their own self (2009).

Lejeune connects the growth of the diary form starting in the late Middle Ages with two major time-keeping developments—the mechanical clock and the annual calendar. Between the fourteenth and seventeenth centuries, these inventions enabled diarists to record life in a series of daily reflections. Of course, as Lejeune explains, a diarist does not write every second of the day—the daily entry for a 24-hour period might be written in 10 minutes. In this way, the diary works like a sieve. Its worth lies in what the diarist records, and what is left out. Lejeune likens the diarist to an artisan, like a sculptor or an artist, who decides what material to include and in so doing shapes

their work. This process of sifting, reflection and contemplation, deciding what to keep and to discard, day after day, creates a valuable means for the diarist preserving moments of his or her life in these diaries.

#### A Series of Dated Traces

This led Lejeune to define the diary as 'a series of dated traces' (2009, p. 179). The 'trace' is usually writing, but may also be an object, drawing or picture, which, when part of a series, embraces the movement of time. Rather than describing a one-off event, the diary's strength lies in being 'methodical, repetitive and obsessive' (p. 179) allowing threads to emerge and form patterns over time. Although uninhibited in choosing what to write, the diarist's accumulation of daily fragments, through repetition and regularity, create their own emphasis, patterns and rhythm. Through my research, I planned to study diary excerpts, to identify and reveal patterns and rhythms that occur when an eating disorder develops. I wanted to explore the disconnection that occurs between body and self and healing and how the re-connection with self might start to take place. Analysis of such excerpts, this review told me, would involve appraising the texts themselves, and placing them in context over a period of time. As noted by Lejeune (2009, p. 178) the diary represents freedom in the recording of thoughts, yet is regimented, defined by the clock and calendar. As such, it also represents a genre of exploration, providing a method for internal reflection and observation, and external analysis. In reviewing dates and entries, patterns can be traced and recognised, allowing consideration of private diary excerpts in a more universal context of experience and life (Quendler, 2013).

Lejeune's enthusiasm for the diary as a literary genre was not universal, however. For centuries, diary-writing had received little systematic attention as an activity or commitment, or on what it meant to be a diarist (Wiener & Rosenwald, 1993). The American writer Susan Sontag (1933–2004), whose diaries comprised almost 100 notebooks (Maunsell, 2011), was among several writers (for example, Vera Brittain, Anäis Nin, Virginia Woolf) leading up to and during the rise of Feminism in the 1960s who raised the profile of the diary (which had been seen as a subsidiary to other literary works) as a document worthy of respect in its own right, as a genre. The work of Sontag on the illness experience has also been influential, for she continually strove to both gain deeper insight and care of herself through her diary-writing, as well as hone her literary skills (Maunsell, 2011). (For more discussion on interest in women's diaries by feminist and women's studies scholars, and on women's history, see Alexander, Brien et al., 2015).

While Lejeune put forward a succinct definition for the process of creating a diary, Paperno (2004, p. 565) observed 'it is a common opinion that scholars do not know what to do with diaries'. Private diaries, Paperno posits, with their blend of personal observations, reflections and facts, elude defined structure both as a genre and cultural phenomenon. Alaszewski (2006a) contends diaries are much more than mere records of events and feelings and a witness to suffering; they also are imaginative, creative works, and a foundation for new works. Fictional writer Kafka (1976), for instance, writes of the need to self-examine in his diary of 7 November 1921:

The inescapable duty to observe oneself: if someone else is observing me, naturally I have to observe myself too; if none observes me, I have to observe myself all the closer.

More recently, the diary, due to developments on the Internet since the 1990s, has entered an ambiguous area between public and private (McNeill, 2003). The diary's functions in this context have been explored, interpreted and applied in numerous ways (McNeill, 2003). Today the diary genre continues to reflect its pre-modern understanding, where diary-writing was considered a deeply private and personal activity, shared with close others if at all, but also embraces the on-line forms of diarywriting, where entries may be shared publicly, and readers may be unknown (de Laat, 2008; Lejeune, 2009; McNeill, 2003). Whether the diary comprises a traditional private pen-and-paper volume, or on-line format, it can be considered as a means for thinking 'through the seam between the private and the public self', allowing the self to emerge through the writing process rather than necessarily as a reflection of the diarist's real experience (Serfaty, 2004, p. 462).

### The Evolution of Diaries

In England, the first known diaries dated from the latter part of Europe's medieval period or Middle Ages (Quendler, 2013; Alaszewski, 2006), which commenced around the late sixth century and continued for about 1000 years. This was a time when feudalism and the spread of Christianity had helped to preserve social order and maintain stability (Quendler, 2013). Apart from some priests, monks and a few nuns who could read and write, literacy was almost non-existent. Any documents were written by hand until invention of the printing press in the early 15th century (Alexander, Brien, & McAllister, 2015). Such documents related mostly to religious life, laws and administrative details (Smyth, 2008; Lejeune, 2009). The diary evolved as the practice of record keeping became more general and writers began to note personal reflections and observations, in addition to historical facts, figures and appointments (Cucu-Oancea, 2013). The diary's first uses, beyond business and commerce reasons, included being a place of confession for people striving to discipline their life within the confines of religion, and a place for people to record their spiritual progress (Cucu-Oancea, 2013; O'Sullivan, 2005).

### Influence of Historical Developments

The opportunity to keep personal records became more universal in the early modern period, 1500 to 1700, when two major historical developments provided the necessary tools for the less privileged and even the lower classes of people (O'Sullivan, 2005). One development was the relatively widespread accessibility of formal education, which led to increased literacy (O'Sullivan, 2005; McKay, 2005). The other was the Protestant Reformation, which heralded social upheavals and the rise of individualism (O'Sullivan, 2005). People from many occupations and positions began to consider their life in relation to self and others in ways beyond the spiritual or religious bonds and constraints of the Church (Heldt, 2005, p. 10). Presented with more choices and opportunities, people were challenged to pursue independence and self-reliance. At the same time, the future became less predictable and people began to use the diary as a means of self-surveillance and self-monitoring (Alaszewski, 2006). They also were

developing a greater awareness of the concept of time and of their life in that context (Smyth, 2008; O'Sullivan, 2005).

As people strove to find new meaning and direction in this life and the next (Alaszewski, 2006b; O'Sullivan, 2005; Robertson, 2010) diary-writing provided a means for defining identity and purpose, and achieving self-understanding (Alaszewski, 2006). In this way, the diary was beginning to have different meanings and purposes for different people. Exploration of the period 1600 to 1800, against a backdrop of religious and political contexts (Mascuch, 1997), attests to the growth of the personal diary. By the end of the nineteenth century, diary-writing had become a common practice among literates in documenting their private life (Cucu-Oancea, 2013).

My main interest in this history of the diary was to explore the diary's evolution as a recording tool of daily activities and events, and as a repository and an outlet for mental and emotional stresses, as this was the focus of my creative work.

#### Writers Who Have Explored Identity In and/or Through Diary-Writing Practice

While not specifically focused on eating disorders, the works of writers who have explored questions of identity and identity formation in their diary-writing practices was important to consider. These writers include Nin (1978), Milner (1981 (1934)), (Woolf, 1977), Brittain ([1933] 1994), Sontag (2008), and Rainer (1978). Each of these writers has used the diary as a tool to document and seek resolution to, and of, personal struggles encountered in the process of creating and writing, and then has drawn on this work recorded in that private way to produce creative texts for the public. For instance, Sontag (1933–2004) used her diary to study and analyse the deepest threads of self, such as doubts and dreams, and process them. The bid to blend the inner and outer self, the dreams with the realities, to create an 'identity just out of reach in the future' (Maunsell, 2011, p. 13), was for Sontag a fulfilling journey and process as long as life itself.

Diary-keeping, primarily a private pastime, has been shown to be helpful in developing many parts of the mind including memory, imagination, feelings, dream imagery and intuition (Rainer, 1978). To focus on only one element, Rainer cautions, however, would be like trying to play a musical instrument knowing only one chord (Rainer, 2004, p. vii). The many uses of diary-writing formats include being a therapeutic intervention tool for trauma and abuse and for increasing understanding of other clinical ailments (Aitken et al., 2013; Baker, Preston, Cheater, & Hearnshaw, 1999; Egerod & Bagger, 2010; Egerod, Christensen, Schwartz-Nielsen, & Agård, 2011; Engström, Grip, & Hamrén, 2009; Pennebaker, 1997b; Perier et al., 2013; Travers, 2011). Examples comprise a rehabilitative intervention to aid psychological recovery in intensive care patients; acknowledging, measuring and providing insights into the experience of patients; and healing of emotional wounds. A study by Chang et al. (2012) indicated that engagement in diary-writing followed by narrating life from an outsider's perspective could assist the healing process. Pennebaker's narrative work in the field of trauma (Baddeley & Pennebaker, 2011; Pennebaker, 1997a); Pennebaker (1997b); (Pennebaker & Chung, 2007; Pennebaker & Seagal, 1999) describes the reflective characteristics of expressive writing in coping with painful emotion. For example, the process of writing as a method of releasing and externalising suppressed traumatic

experience, and progressively reading it back and reflecting on this, can lead over time to the conscious placement and management of the traumatic experience in the context of overall life experience, thus facilitating healing. Furthermore, writing about positive thoughts, feelings and events, as well as disclosing those that are negative, has been shown to be beneficial in achieving improved wellbeing (Range & Jenkins, 2010).

Proponents of 'gratitude journals' (Rainer, 2004, p. vii), including Breathnach (2011), suggest that the diary helps one to see that life is not all bad, and this kind of use also assists in connecting with the 'self'. For someone who defines themselves by their eating disorder, a shift in identity toward a more complex sense of self is crucial to their recovery and ability to re-enter mainstream life. I aimed to explore how the diary could assist in the construction of identity, which would involve the writer in re-scripting and developing a more realistic and deeper understanding of themselves and their emotional and physical needs (Cruzat-Mandich et al., 2015; Hodge & Simpson, 2016; Progoff, 1977). Progoff was a pioneer in revealing the diary as a tool for cultivating personal growth, in and by which the diarist could strive to harmonise the rhythms of the inner and outer parts of their life (Rainer, 2004, p. 9). In this way, Progoff's view of the diary's ability to connect all parts of self reflects that of Lejeune (2009, p. 179).

## How Diaries Have Been Used as a Research Tool

The use of diaries as a data-gathering tool has evolved since the early 20th century in researching facets of the human condition (Kaun, 2010). However, referring to Gershuny and Sullivan (1998), Kahn posits that discussion was lacking in some areas of this practice, for instance the diary methodology in relation to open-ended qualitative

formats. The focus of such methodology was on subjective circumstances and observations of social occurrences. Narratives in such diaries, which were free of boundaries and limits imposed by the researcher, can help present a more intimate picture of the diarist's identity and offer opportunity for the researcher to gain fresh perspectives from original accounts (Burgess, 1999). At the same time, diarists are not constrained or influenced by a certain interview situation, focus group discussions, or participatory observation by the researcher.

Observation of how the diary is written and incorporated into the routine of a diarist's everyday life can be used to understand the perception and interpretation of the private versus public spheres (Kaun, 2010). Furthermore, temporality and perspective are constructed through the narration of past events and future plans (Serfaty, 2004). Thus, diaries as data present the researcher with a challenging combination of open-endedness and closure of the material (Serfaty, 2004).

While pen and paper continue to be employed as data-gathering tools (L'Abate & Kaiser, 2011), digital formats are beginning to be used in many aspects of health services. On-line therapeutic interventions incorporating diary techniques as a component of stepped care are likely to become routine among adults with chronic health conditions (Lim, Sacks-Davis, Aitken, Hocking, & Hellard, 2010), but more focus is called for, for instance, in evaluating the application of such technologies into clinical practice (Beatty & Lambert, 2013) and a range of related ethical, privacy and policy issues.

#### Using Diaries as a Research Tool in The On-line Environment

It was important to explore this area because the on-line environment, in which some of my data gathering was conducted, is a place where cultural rules and ethical boundaries relating to diary-writing can become blurred and be tested. Such an environment may raise questions of self-regulation and responsibility for the researcher working with online methods (Kanuka & Anderson, 2007). Participants may develop a feeling of anonymity and expose information which they would not give in other contexts. Especially in research methods that used pre-existing material, the basic principles of anonymity and informed consent are challenged because the researcher can argue that the individuals are exposing themselves voluntarily in a certain part of the public sphere (Kanuka & Anderson, 2007; Serfaty, 2004). Observers seeking informed consent, therefore, need to explain to the participants how material about them will be used (Serfaty, 2004). In general, ethical standards for research are challenged in on-line environments because boundaries between public and private are not distinct; however, the participation in on-line studies is not more risk-prone than in studies that are offline (Kaun, 2010). Each specific research project requires risk assessment evaluation (Kraut et al., 2004; Sudweeks & Simoff, 1999). In relation to on-line research, the work of Kraut and others identifies ethical challenges, such as the treatment of research participants and the data security of material collected on-line, and the quality of data in terms of contacting and recruiting participants. Instead of trying to make former standards and ethical guidelines fit the new situation created on the Internet, development of distinct

and adjusted standards for on-line research is needed (Fry & Schroeder, 2009; Jankowski, 2010). I discuss how I dealt with these issues in Chapters Two and Three.

Additionally, since the 1990s, on-line research has provided researchers with certain advantages. For example, on-line tools for storing diaries has made data management and interpretation easier, while e-mail and on-line blogs have made it simpler for the researcher to keep in contact with the diarists. As with the traditional diary format, on-line diaries kept over a longer period also allow for development of a triangular relationship between the diarist, the diary, and the researcher (Kaun, 2010). However, by using the technical infrastructure of the Internet as the connecting medium over time and distance, research can be not only more efficient but potentially more informative. As such, researchers can reach new groups of informants more easily (LaMarre & Rice, 2016a) and through regular dialogue create a foundation of trust. Siles (2012) draws on Foucault's theories of subjectivity in conceptualising early blogging and on-line diary-writing as a technology by which the individual discovers and reveals their self. This on-line form of open diary-writing, emanating from an innate sense of trust and connection with like-minded others, was found to be helpful by myself and others in maintaining recovery from an eating disorder. As posited by Hensel (2014) the person-centred on-line platform can provide flexibility for individuals to write and share entries at a time and in an environment that best suits them, potentially helping them to feel more relaxed and secure in divulging delicate information. Furthermore, Broom et al. (2015) postulates that this participant-driven form of narrative construction can provide a new perspective of illness experience.

## Narrative Medicine: Understanding The Illness Experience

Narrative medicine is an approach that complements and encourages this exploration of the lived experience. This medical approach, which began to evolve in the latter half of the 20th century (Charon, 2001; Hurwitz & Charon, 2013), acknowledges that the patient's story is an important factor in promotion of healing. The narrative medicine approach (Charon, 2009; Frey & Keränen, 2005; Greenhalgh & Hurwitz, 1999; Kalitzkus & Matthiessen, 2009) complements and enriches the biomedical model by advocating greater dialogue interaction between patients and practitioner. The method provides a means for physicians to better understand their patient and their patient's illness through the process of story-telling and story-listening, and for researchers to include the patient's story in scientific work. Writing illness narrative from the patient's perspective also can serve important therapeutic and healing functions (Baddeley & Pennebaker, 2011; Bingley et al., 2006; Bolton, 1999b, 2008; Charon, 2006a; A. W. Frank, 2010; Jørring & Jacobsen, 2014; Pennebaker, 1997b; Pennebaker & Chung, 2007; Pennebaker & Seagal, 1999). One drawback perceived in research applying this more patient-centred approach is the lack of a clear-cut measure by which to judge its effectiveness. There is no clinical gauge or blood test to measure feelings, spirit or emotion. However, narrative processes can assist the expression of emotional and psychological aspects, not in isolation but in relation to other details which affect the patient's life, such as physiological, historical, economic and moral aspects (Dawson et al., 2014a). This is exemplified in *The words to say it*, an autobiographical novel by French writer, Cardinal (1929-2001). Her work provides a personal account of therapy

and change, and an illustration of how words can be used to help cure oneself. To focus only on the patient's story is ineffective but the very process of written narrative over time can benefit the patient and complement the clinician's depth of medical knowledge, providing the basis for understanding, action, and care (Charon, 2014; Childress, Charon, & Montello, 2002). Furthermore, the method can counter possible deficiencies in providing a full picture by including insights from close others, including caregivers, health professionals and researchers. While evidence is scarce on the use of the diary in therapeutic approaches in the eating disorder field, patients are becoming more resourceful and expectant of collaborative and patient-centred care, adding impetus to include their stories in therapy (Darcy & Dooley, 2007; Dawson et al., 2014a).

#### How Diaries Have Been Used In Healthcare

Besides historical and data-gathering significance, there has been a growing realisation that the diary is a useful therapeutic resource in the healthcare field. Patients and service users who have kept diaries are creating a valuable archive of healthcare-related stories that can affect, change and benefit clinical practice (Haigh & Hardy, 2011). For instance, the diary's ability to go beyond the mere recording of fact make it a rich source of material for memoirs, and a memoir drawing on and analysing a diary can offer insightful accounts in healing (McAllister, Brien, Alexander, & Flynn, 2014). Rainer (2004), however, in observing that the diary's ability to heal has been increasingly acknowledged in many forms of health care (p. vi), warns that various Internet tools are effective only when adhering to the original diary's basic elements of healing, creativity and spirituality (p. vii).

Being set in a particular moment in time, each diary entry portrays everyday life. For the researcher, clinician, or health provider, the study of diaries over time can provide clues on the patient's condition, which may not be apparent in any other way (Webster, Lu, & Henning, 2014). Verbrugge (1980) and Plummer (2001), proponents of the diary as a research tool, also extol its use as a therapeutic tool in offering observations on daily life, an intimate familiarity with the diarist's experience of the present, and the wider context of an 'ever changing present' (Plummer, p. 48).

Two main types of diaries may be used in healthcare. Solicited diaries are those sourced by the researcher for a specific purpose (Elg et al., 2011), and over a specific time (Elg et al., 2011). The unsolicited or private diary, drawn on in my research, has the advantage of an innate ability to be diachronic, pertaining to a timeframe, and synchronic, a moment in time, encapsulating and integrating the personal experience of illness (C. Breathnach, 2016, p. 92). Using unsolicited diaries means that every diary entry relates to a particular moment in time and, date-by-date, records a continually changing present. Each entry announces, *'I am here, and it is exactly now'* (Fothergill, 1974, p. 9). In the case of a diarist with a chronic illness, such as an eating disorder, this contemporaneous flow of entries may provide a way to gain insight into what can be a dire and isolating experience.

#### Developing The Personal Diary On-line

Technological advancements that accompanied the Internet's development in the 1990s have enabled the blog, a personal website or web page on which a person can express thoughts and feelings on a regular basis, to build on the foundation of the traditional

pen-and-paper diary. Blogging provides a tool by which a person can publish the modern day equivalent of a personal diary on-line (M. Jones et al., 2014). Similarly to evolution of the paper diary as a recording and self-exploring tool, the use and availability of on-line diaries and blogs have increased, as more people become computer literate and the technological tools more accessible.

Lejeune describes the diary in all its forms as a democratising form of literature and 'a meeting with the self, over the course of time, and as a possible point of meeting with others' (Fanning, 2011, p. 219). Like Rosenwald (1987), Lejeune considers the dating of entries a defining character of the diary (Lejeune, 2009, p. 218). Blogging meets this criterion and even while the practice was in its infancy in the 1990s, Lejeune was including this digital form of personal writing in his definition of the diary. For him, new media and culture were as worthy of study as text and tradition. Such acknowledgement was an important and welcome finding in this literature review because some of my research participants submitted blog extracts as diary entries. Popkin and Rak, editors of Lejeune's collection of essays, *On Diary* (2009), described Lejeune as an inter-disciplinarian who ignored the academic rigidities that excluded many diaries from consideration in scholarly and educational works (Chansky, 2012, p. 231).

## The Complexity of Eating Disorders

An eating disorder is a serious mental and physical illness with patients at risk for premature death (Spotts-De Lazzer & Muhlheim, 2016). Classifications of eating disorders in the latest Diagnostic and Statistical Manual of Mental Disorders (DSM-5)

include anorexia nervosa, bulimia nervosa, BED, and other specified feeding and eating disorders (Sysko et al., 2015). The illness, as described in the DSM-5, is complex with a lack of consensus in the eating disorder field on causes and treatments (Spotts-De Lazzer & Muhlheim, 2016). Anorexia nervosa has the highest death rate of all psychiatric illnesses (Dawson et al., 2014b; Kaye, 2008). Eating disorder recovery is not easily defined (LaMarre & Rice, 2016a) and remains the object of continued debate in conventional and critical literature on eating disorders (Bardone-Cone & Cass, 2007; Kordy et al., 2002; LaMarre & Rice, 2016a; Noordenbos, 2011b). Often, objectively measured physical signs and symptoms such as weight loss or gain, BMI and blood tests, tend to be used by clinicians as markers of recovery progress in patients suffering from eating disorders—for example, Accurso et al. (2014)—sometimes to the extent that other factors, including the patient's story, are attended to only after weight restoration and 'normalised eating'—for example, Lock and Le Grange (2012).

The patient's story is vital to understand because it embodies the lived experience of eating disorders, an area explored in the literature but unfortunately rarely applied in routine clinical practice. Recovery efforts have been referred to as a process of finding oneself (Noordenbos, 2011a, 2011b), regulating emotions without using symptoms (Federici & Kaplan, 2008) and becoming whole again (Jenkins & Ogden, 2012).

With anorexia nervosa which, as noted (Kaye, 2008; Dawson, Rhodes & Touyz, 2014), has the highest mortality not only among eating disorders but any mental illness, the process of moving beyond the illness characteristics of resistance or denial to

engagement in treatment and commitment to change, and the moment when this occurs, moving from an ego-syntonic state to an ego-dystonic state, has been termed the tipping point in recovery (Hays, 2013; Dawson, Rhodes, & Touyz, 2014). At this point, when ego-syntonic thoughts are able to dominate, motivation increases, allowing the person with the eating disorder to recognise and take action against their illness thoughts, eventually enabling them to reflect and rehabilitate. Insight through patientcentred story-sharing into the personal and complex experiences of such tipping points appear vital for clinicians, family, caregivers and patients to understand because they may signal the re-emergence of hope, motivation, self-efficacy, and support from others in the recovery process. For further perspectives and studies on lived experience in relation to eating disorders see, for example, works by (LaMarre (2016b); Sheens (2016), Kiesinger (1995), Del Busso (2009) and Tillmann (2009)).

However, challenges persist in the eating disorder field (LaMarre, 2016) due to illness effects that include isolation, shame and stigma (Dayal, 2016). For instance, difficulties remain in relation to the ability to access and connect with a patient's innermost thoughts and with encouragement of motivation to change (Schmidt, 2002; Hay, 2013). Deeper understanding of the eating disorder experience, Breathnach (2016) posits, can be addressed through the study of unsolicited diaries, the text of which may illuminate and touch on areas not raised in patient/practitioner dialogue (p. 96).

#### The Vicious Cycle of Ego-dystonic and Ego-syntonic Thoughts

The process of recovery is particularly challenging for people with eating disorders because they are often severely affected by ego-dystonic and ego-syntonic thoughts,

and become embroiled in a vicious cycle that is considered a key point in the enduring nature of this illness (Fairburn, 1999; Schmidt and Treasure, 2006). An ego-dystonic thought is described by Purdon et al. (2007, p. 200) as 'one that is perceived as having little or no context within one's own sense of self or personality.' For example, unable to verbalise they are too afraid to eat an ice-cream that a friend has bought, a person with anorexia nervosa may deliberately drop the ice-cream on the ground, and immediately feel deep shame at their behaviour. Unwelcome and intrusive eating disorder thoughts like this can cause emotional distress and are resisted or suppressed because they are processed and experienced as problematic and threatening.

Ego-syntonic thoughts, feelings and behaviours, are those that are consistent with the self-view of the person. For instance, the feeling of intense hunger may be considered a positive sign of control over food, weight and body, and even persistent, uncomfortable urges to eat are experienced as a sign that one needs to and can endure hardships that others just do not have the special abilities to confront. Schmidt and Treasure (2006) postulate that such positive beliefs are a key factor in explaining the maintenance of an eating disorder. However, the same symptom, like a fixation on certain weight, can be experienced as both ego-syntonic, where there is a sense of greater self-control and motivation to achieve goals seen as positive, and ego-dystonic, where there is disruption in social activities and a lowering of mood, due in part to the preoccupation, if not obsession, with certain beliefs and anxieties. (Belloch, Roncero, & Perpiñá, 2012). Eating disorder patients in a study (Roncero, Belloch, Perpiñá, & Treasure, 2013) analysing the extent to which unwanted eating intrusive thoughts about

weight, diet, exercise and so on, are ego-syntonic and/or ego-dystonic, indicated that these thoughts were experienced as rational and simultaneously undesirable and immoral. This suggested that such thoughts were not fully ego-syntonic or ego-dystonic (p. 67) and future studies were recommended.

Such ego-dystonic and ego-syntonic thought dysfunction, according to Roncero, can deprive the patient of the ability to view their identity beyond that of their eating disorder. Higbed (2010) and Vandereycken (2006) posit that a person with anorexia nervosa, for instance, typically does not view their symptoms as part of an illness but as an ego-syntonic part of their identity, which explains why they see their symptoms as perhaps welcome, and necessary, and therefore not needing to be eliminated. The combination of ego-dystonic and syntonic thoughts may also explain in part why distressing—and sometimes haunting—thoughts are interpreted as one's failure to live up to rational, idealised goals that constitute the person's only path to uniqueness, security, and salvation. Although both ego-dystonicity and ego-syntonicity are generally considered key features of eating disorder symptoms, and are explored in the literature, how the co-occurrence and blending of such thoughts can be explained, and be challenged by a person, has not been discussed in the literature and, in my experience, has not been applied in practice. This therefore provided an opportunity for me as a creative practitioner to explore and illuminate such thought struggles and explore the complex nature of 'denial' and 'resistance'—if evidenced in the diary entries of my research participants. For further explanation of ego-dystonic and ego-syntonic thought processes refer to Belloch and Higbed (2010, 2012).

Two major categories of denial are noted to occur in a person experiencing an eating disorder. The person may experience denial that their experiences and behaviours are 'anybody else's business', let alone 'symptoms of an illness', and also the denial of their true body size and shape; for instance, a reflection of the body in the mirror will appear much larger than reality (Kaye, 2008). Besides an inability to see that thoughts driving what to others are so obviously self-harming behaviours are due to an illness, a person with anorexia nervosa often may also experience avoidance of self-disclosure, due to debilitating fear of consequences based around food and weight (Arnold, 2012). This combination of factors results in a reluctance to initially access a health service and subsequently to accept or persevere with therapeutic assistance (Treasure & Alexander, 2013). The effects of this disconnection of mind or self from body may be revealed through diary-writing, with entries over time recording how the diarist inadvertently strengthens their illness and compounds self-disintegration, for instance, through self-berating over failure to adhere to the latest diet and exercise rules.

## The Relationship Between Mind/Self and Body

Milner (1900–1998) reveals a similarity with the challenges experienced by people caught in the tension of ego-syntonic and ego-dystonic thoughts. Milner used diary-writing to learn about herself and, under her pseudonym, Joanna Fields, published a number of works, including the autobiographical *A life of one's own* (1981 (1934)), and its companion, *An experiment in leisure* (1986 (1939)). Both works, based on Milner's diaries, illustrate an early self-absorption with comprehending, finding meaning for and

expressing experiences of body and mind (Gower, 2012). In *A life of one's own*, referred to by King (2013) in the article 'Creative writing in recovery from severe mental illness', Milner observed 'it was gradually dawning on me that my life was not as I would like it and that it might be in my power to make it different' (p. 19). Milner explored her consuming interest with the relationship between mind and body in her final book, *Eternity's sunrise: a way of keeping a diary* (1987b), by piecing together excerpts from earlier texts and diary entries. Haughton (2014) describes this book's final chapters as embodying a complex blending, discarding and weaving of moments, diary entries, commentary and memory in one textual palimpsest (p. 361).

The self-contradiction reflected in Milner's on-going drive and use of the diary in the continual integration and disintegration of works to create a new work provide a striking resemblance to the traits of an eating disorder and the associated pull of disconnection and re-connection between body and self experienced by a person with an eating disorder. Milner's writing process also strongly relates to my creative practiceled method in addressing the research question: *How can diary excerpts be used in writing a book to assist people with eating disorders?* 

A person with an eating disorder may become excessively preoccupied with their body weight or shape (Couturier, Kimber, & Szatmari, 2013) unknowingly leading to disconnection from self. In this way, the eating disorder may befriend the sufferer (Treasure & Alexander, 2013), offering a coping, 'trust me' mechanism that thrives on isolation and secrecy (Basile, 2004), dominates self and causes life-threatening disembodiment. Excerpts from my diaries, and those of other research participants,

would reveal how the diary itself could develop into a foe under the pretence of being a friend. Diary entries over time would reveal the development of symptoms and the alignment of thought processes with the eating disorder, including regimented rules and regulations as a means for getting through each day. The entries would illuminate how the eating disorder, anorexia nervosa, is characterised by the ego-syntonic nature of symptoms, denial of illness, and ambivalence about treatment engagement (Berkman, Lohr, & Bulik, 2007; Dawson et al., 2014a; Higbed & Fox, 2010). The entries would show how increased reliance on dominating illness thoughts (Pugh & Waller, 2016) that monitor the diarist's eating, weight and shape, and insist on punishing behaviours to restrict or compensate, adds to the daily challenges. Research (Dawson, 2014; Higbed, 2010) examining the patient's perspective reveals that the struggle to make sense of, and recover from, the illness, is assisted by viewing the illness as separate from the self. Diary excerpts from research participants would reveal how the diary can be used to facilitate this challenging process.

#### Eating Disorder Recovery and the Patient Perspective

An orientation toward personal recovery has become central to mental health policy in many Anglophone countries, including Australia (Shanks et al., 2013). A systematic review (Leamy et al., 2011) identified that personal recovery in mental health in general involved five recovery processes, comprising connectedness, hope and optimism about the future, identity, meaning in life and empowerment. Theories of recovery as a personal process have largely emerged from patient experience with psychosis (Jacobson & Greenley, 2001; Morrow & Weisser, 2012). An extensive

qualitative study by Kogstad et al. (2011) found that recovery for people with mental health issues was basically a personal process. The process, the Kogstad study noted, could be facilitated with external psychosocial and material support. In Australia, the personal approach to recovery has become central to mental health care policy and standards (Butterfly Foundation, 2016).

However, recovery oriented approaches for people with eating disorders might require a different emphasis (Butterfly Foundation, 2016) to that of other mental health challenges. For example, the 2016 Butterfly study revealed a need for more positive professional and early intervention responses to help-seeking; greater understanding of recovery as a long term process; more focus on thoughts associated with eating disorders instead of weight and appearance; a supportive healthcare environment; and a health workforce informed by the experience of people with eating disorders.

Understanding of eating disorders has expanded greatly since the classic works of Bruch (1978) when the illness was considered to mostly affect young females from wealthy families in Western society. Eating disorders have been revealed as serious mental illnesses that affect people from all ethnicities and ages, in both developed and developing countries (Mitchison & Hay, 2014). They are associated with significant physical complications and have the highest mortality rate of all psychiatric illnesses (Arcelus et al., 2011). Illness characteristics include disturbances of eating behaviours and a central psychopathology focused around food, eating and body image concerns. There are different types of eating disorders. The DSM-5 (Hay et al., 2014) defines diagnostic criteria for anorexia nervosa, bulimia nervosa, binge eating disorder, other

specified and unspecified feeding and eating disorders, and avoidant/restrictive food intake disorder.

In a discussion on evidence-based practice in eating disorders, Peterson et al. (2016) noted three essential components for eating disorder treatments: research evidence, clinical expertise, and patient values, preferences, and characteristics. However research on the effects of treatment preference on outcome and attrition among patients with eating disorders was minimal and Peterson (2016) posited that empirical support and patient preferences for treatment were not consistently considered in the selection and implementation of eating disorder treatment. While current research supported the use of psychotherapies, including cognitive-behavioral, interpersonal, and family-based therapies, as well as certain types of medications for the treatment of eating disorders, the research limitations indicated a need for greater investigation on integrating clinical expertise and patient perspective (Peterson, 2016). Although literature was scarce, some researchers (Bird et al, 2014; Dawson, Rhodes & Touyz, 2014a; Mitchison et al., 2016) were proposing that the personal recovery model, for example with a focus on improving quality of life, could assist people with eating disorders, and that prevention and intervention strategies should focus more on addressing patients' concerns (Diaz Martinez et al., 2016).

Narrative therapy was one approach suitable for the personal recovery model in eating disorders. This form of therapy suggested the need for the patient to 're-author' their problem-saturated stories (with the help of therapists), and also made clear the importance of specific social, political, cultural and historical contexts for constructivist

approaches to narrative. Beels (2009) described narrative work as an open and transparent consultation, with the therapist influencing the outcome by guiding the patient with questions in a way that helped them to define the problem. The questions aimed to help the patient find a narrative space essentially free of resistance to change. From that space, supported by the framework of the questions (White, 2001), patients could start to construct stories, interpretations, and communities that overpowered and externalized barriers to their recovery. However, more experimental and evaluation research was required to increase the evidence-base for the use of diary-writing as a therapeutic approach in clinical practice. For example, qualitative research, posited by Mackrill (2008), to compare diary writing with and without therapeutic intervention, could provide a useful method of evaluating the effect of diary-writing as a therapeutic tool in the treatment of eating disorders, and a means of advancing knowledge and understanding in the patient-centred recovery model.

#### The Diary as a Self-help Mechanism

Over time, for a patient recovering from a chronic illness like an eating disorder, the diary can offer a self-help mechanism by enabling reflection and the opportunity to gain fresh perspective (Breathnach, 2016). Multiple aspects of a person's life also can be tracked through patterns that emerge in a diary, including trauma (Gentile, 2007; Hodge & Simpson, 2016), illness symptoms, activities (Milligan, Bingley, & Gatrell, 2005), routines or coping mechanisms (Mackrill, 2008) or the concerns or pursuits of personal agendas. The process of writing can provide therapeutic benefits and be a positive influence on the interaction with health professionals involved in the patient's

treatment (Anyaegbunam et al., 2013; Bolton, 1999b, 2008; Charon, 2006a, 2007, 2009). The diary also can provide a communication tool by being a repository for thoughts and reflections between consultations (Alexander, McAllister, & Brien, 2016). This has been the author's own experience with a psychiatrist over many years (Alexander et al., 2016).

Breathnach (2016) posits that one way to increase understanding of the illness experience is to explore a more unstructured source, like the unsolicited diary. In making a case for the unsolicited diaries to be accepted as a valuable resource for research, teaching and learning in the medical humanities, Breathnach (2016, p. 92) contends, however, this will be possible only if scholars give the diaries due consideration. While the narrative medicine approach (Charon, 2009) in recent decades has encouraged and advocated greater dialogue interaction between patients and practitioners, gaps remain in patients' abilities to access and connect with innermost thoughts and for their clinicians to be aware of them. Such gaps, Breathnach argues, can be addressed through the use of unsolicited diaries.

## Conclusion

This literature review reports prominent themes relevant to this creative practice-led research project. The literature reveals promising evidence on the use of diary-writing as a research, self-healing, therapeutic and literary tool generally, and evidences the reality that the diary continues to interest researchers and that knowledge is growing about its value and utility. While findings are scant in my specific interest area of the diary in relation to the eating disorder field of healthcare, the diary's use as a research tool in this field, and as a self-monitoring, self-understanding treatment strategy, and

communication tool, is expanding. However, I found a dearth of literature, with the exception of Milner, where the diary is used as data to create new work, which led me to my research question: *How can diary excerpts be used in writing a book to assist people with eating disorders?* 

# Chapter Two: Methodology

## Introduction

In the preceding chapter, a significant gap in the literature was revealed in the use of personal diaries as a data source for writers. This gap became the subject of my research in order to strengthen and enrich my creative work. In this chapter I outline how a practice-led methodology is used to research and answer the question: *How can diary excerpts be used in writing a book to assist people with eating disorders*?

## The Design: Creative Practice-Led Research

Creative practice-led research allows an examination of the nature of practice and leads to new knowledge that has useful meaning for that practice (Brien, 2006). The writing practice may ebb and flow as the writer, with the influence of personal experience and professional expertise, preferences, likes and dislikes, proceeds to engage in an on-going process of creation and refinement that involves drafting, reflecting and redrafting, plus sharing and discussing, over and over again.

Theoretical works drawn on in order to refine this methodology for the project include Charon (Anyaegbunam et al., 2013; Charon, 2000a, 2000b, 2001, 2006a, 2007, 2009, 2012, 2013, 2014; Charon & Trautman, 1995; Charon & Wyer, 2008), Brien (2006), Schön (Fichter, Quadflieg, & Lindner, 2014; Schön, 1989, 1992; Schön & DeSanctis, 1986) and Pedgley (2007).

#### Narrative Medicine

Narrative medicine, which enables patients and caregivers to voice their experience, to be heard and valued, related strongly to my research aim of allowing people with eating disorders to describe their illness experience through private diary excerpts. Charon, who first used the phrase 'narrative medicine' in 2000 (2007), forged new ground in improving patient-clinician relations. Charon noted how the study of literature provides several important benefits for medicine and medical education. Historically, medicine entered the narrative realms through qualitative social science, especially sociolinguistics, as a way of representing and understanding the conversations between doctors and patients. Charon (2006b) describes medical practice as taking a step forward when scholars made medical discourse open and responsive to inspection and analysis. Around the same time, the benefits of listening to the patient's story, and understanding their perspective of illness, began to become clear. In this way, the qualitative social sciences formed a bridge connecting medical practice with literary theory. Narrative medicine, Charon explains, is about creating a compassionate, corporeal practice that simultaneously heals the patient and nourishes and sustains the doctor.

Narrative medicine alerts one to issues that are beyond medical deficiencies and include illness and wellbeing experiences. Creative writing and writing therapy, for instance, might reveal epiphanies or struggles, as part of a process that may provide benefits for participants in both individual and community settings (Neilsen & Murphy, 2008a, 2008b). I wanted to include such insights in the research project because they

might assist a person with an eating disorder to widen their view of illness and begin to identify that while their struggles are unique, they are not alone in their experience. Unsolicited diary excerpts would provide a means of achieving this research goal. I required a practice-led methodology that would permit a work to be constructed from the stories revealed in diary entries. The methodology would require constant guidance and interaction with the research participants, critical testing of the stories against their own moral knowledge, and a good sense for the right time and context in which to share their story. This was important in my project, as the aim with the book was to show a way to more fully represent the patient's experience and voice and to provide a more complete communication, with more insights from dark corners not yet revealed, and more understanding of the illness experience.

#### Interlinked Components

Creative practice-led research draws on a combination of creative acts and research knowledge from both personal experiences and structured studies. Research and practice are reciprocal, with more emphasis on data creation than data collection. Brien explains that in creative writing this practice-led research approach comprises interlinked components, including, although not exclusively, the physical act of writing and producing a new work. It also involves copious amounts of reading and rigorous honing of reflective and observational skills to assist in understanding the process as well as the thoughts and steps that explain and illuminate the creation of the new work. Unlike a scientific experiment, which has a defined beginning and end, the creative writer requires a deep affinity and association with their work to decide when it is

complete. An intuitive and intimate understanding of how the data can be most usefully portrayed in a new work to inform, engage and entertain enables recognition of points at which the addition or deletion of text will make the work more complete.

## **Reflection In and On Practice**

Schön's seminal work on reflective practice, which emphasised the role of self-reflection, was also vital for my project. Time was required in adjusting to initial unfamiliarity and unlearning early beliefs or expectations in the data-gathering process, in order to master the art of writing and to move continuously back and forth between reflection on and in action. Reflection-in-action, which can be described as learning by doing and improvising as one goes along, involves examining experiences, connecting with feelings and attending to theories in use. It may include active guidance by an expert in the field, in facing issues, testing solutions, making mistakes, seeking help, and refining approaches. This process of thinking on one's feet would be valuable in my creative work and would later link with reflection-on-action through the sharing of chapter drafts with readers and research participants. Such practice would entail building new understandings to inform actions in situations that were unfolding, examining text relevance in addressing the research question, and would lead to the creation of further responses and decisions. In my exploration of the diary and its place in medicine and literature, I found this observation from Schön to be especially relevant:

The practitioner allows himself to experience surprise, puzzlement, or confusion in a situation that he finds uncertain or unique. He reflects on the phenomenon before him, and on the prior understandings that have been implicit in his

behaviour. He carries out an experiment that serves to generate both a new understanding of the phenomenon and a change in the situation. (Schön, 1983, p. 68)

Reflection in and on practice involved examining my attitudes, thoughts, reactions and behaviours to comprehend and view my position in relation to others, as demonstrated in the works of Bolton (2010) and Holloway and Biley (2011). This process required me to examine my involvement, and become aware of my knowledge limitations and how my behaviour might impact on others (Clancy, 2013). While sometimes arduous and essentially inquisitorial in its approach, this active process was vital to achieve self-awareness and accordingly the ability to recognise and consider any effects that could influence data collection or analysis. Besides being constantly mindful of the contributions of all research participants and also their welfare, I needed to ensure the reflexive process used in relation to interpreting my own diary was rigorous. For example, I was conscious of the observation of Elliott (1997) that while participantdriven data meant direction of the research focus might not be possible to the extent, for instance, possible in face-to-face interviews, there were important benefits in allowing the participant to reflect and share the parts of their story that were considered important to them.

Skills honed during a professional writing career in print journalism and previous book researching and writing, together with personal eating disorder experience, assisted me in the process of resourcing and interpreting research participant narratives. Importantly, while able to empathise with participants, due to a shared illness

experience, there was a constant awareness that each diarist had their own story to tell. Ethically, the aim with the creative practice-led approach was to respect and honour the diarist and their stories, and guard them from the risks of harm, discomfort and inconvenience.

The practice-led approach enabled my research project to be a mutually shared experience for both the research participants and myself as researcher. This method cultivated a foundation of trust and provided a platform from which to make connections, identify themes and understand the complexity of feelings and thoughts relating to the eating disorder illness and the self. An understanding of differences between illness thoughts and non-illness or self-thoughts was critical to the project. The way of looking at the conflict between a person's motivations that were driven by the disorder and the cognitive distortions that arose, and a person's motivations to get well and recover from an eating disorder, were informed by Narrative Therapy. Narrative Therapy was developed by White and Epston (1990) and continues to be used in practice and discussed in the literature by others. This approach is considered postmodern because it moves away from standard therapeutic approaches, and decentres the power and expertise of the therapist, in favour of the patient. The therapeutic approach involves listening to the patient, asking questions that help them to see that their identity and their future are separate from the illness identity, and encourage exploration of the self in ways that distances the disorder from the self (Lock et al 2005).

The book makes heavy use of an externalizing discourse (Ricks, 2014), which imagines the self without the cognitive distortions that are generated by severe eating

disorder. It also takes an outward focus to encourage readers/clients to look to the future, rather than inwardly and backwardly towards their illness state (Beels, 2009). Through looking forward instead of within, possibilities could begin to generate and the illness thoughts could be separated, inspected and challenged (Lock, 2005).

Understanding the effect of the eating disorder was vital in building resistance to the illness and in helping the patient to place their illness experience in context of their life story (Phipps & Vorster, 2009; Ricks 2014). A qualitative study (Cruzat-Mandich et al., 2015) posited that construction selfhood was a component of successful treatment, and involved the patient developing a more realistic and complex understanding of their emotional and physical needs. The research participants adopted terms like 'true self', 'true identity', 'authentic self' and 'authentic thoughts' as a strategy to strengthen selfdefinition (Schlegel et al., 2009; Wilkin, 2006). Such terms, which were used interchangeably and appeared frequently in the diary excerpts, were shown to support recovery efforts by assisting the recognition and dismissal of illness-laden thoughts. Recovery involved the development of a greater awareness about thoughts that were obsessions generated by disordered thinking, for example, the delusion that beauty and acceptance is dependent on starving, and thoughts that were reasonable and rational, such as 'I am struggling to resist self-harming thinking today, so I will seek help'.

The practice-led method also involved sorting, mapping and organising data in relation to the main topics and threads as they became evident (Ritchie & Spencer, 1994). My process was similar to that outlined by Brian (2015), in that collaboration with research participants involved familiarisation, identifying a thematic framework,

indexing, charting, mapping and interpretation (p. 550). Such collaboration also required continual revisiting to ensure the many parts of the book together made a seamless whole.

#### The Nature of Writing Practice

The findings of Pedgley (2007), who considers practice-led research is largely based on personal experience and is predominantly focused on the creative practices of the self, also resonated throughout in my work. Pedgley explains that personal experience is a major influence on the nature of creative practice. Conscious exploration and reflection on the art and practice of personal diary-writing, while concurrently writing the creative work, promotes improved articulation of creative writing practice and sharing with others. In this way it also can contribute to new knowledge in the field of endeavour and encourage mindfulness that an important aim, as a practice-led researcher, is to make publicly available the discourse that hitherto has been private. Transparency, and willingness to be open about one's own creative processes, assists this aim (Brien, 2006).

Besides describing the conception, development and study relevance of the project, the undertaking of meaningful reflection, analysis and speculation on the creative work and its outcomes would help to make the work credible and distinctive. Autobiographical writing also featured in this reflective practice, requiring myself as researcher to be a complementary ethnographer of my own journey, that is, simultaneously observing, analysing and reporting my own thoughts and actions.

Each of these ideas, drawn from the works of Charon, Schön, Brien and Pedgley, combined to suit my research quest for a methodology that was practice-led and

participant-driven. Such a process would meet my purpose in creating a book that advances knowledge about the practice of first person narrative, primarily through diary-writing. Creative practice-led research allows for drawing on the established literature too, but the emphasis relates more to using this as a basis for thinking things through rather than for pursuing traditional, textbook protocols. Another example of this can be found in the works by Williamson (2013, 2014), which illustrate how the process of creative practice can come to be defined as a feature of self. The practice-led method, through employment and application of first person narrative, would be integral in my creation of a non-fiction book.

#### Method

A method was required that would allow investigation of how diary excerpts could be used in writing a book to assist people with eating disorders. The five main methods used to assist in the data collection of material for the book and the exploration and reflection on the writing practice are discussed in the sections below.

- 1. Recruitment of participants
- 2. The sourcing of diary excerpts
- 3. The selection of diary excerpts
- 4. Ethical conduct
- 5. Rigour

## **Recruitment of Participants**

In this project, creative practice-led research is used to select and appraise diary excerpts for the effective ways they can be used to write a coherent, and compelling book that may help people with eating disorders. Following ethical approval, I began recruitment of research participants through on-line sourcing, with an invitation in a blog post. My invitation included this excerpt:

I welcome interest particularly from people who have had, or have, an eating disorder, and also caregivers (families, partners, siblings) and health professionals (clinicians, therapists, social workers) who have found journaling or diary-writing a comfort and an effective way to sort feelings and thoughts, to debrief and connect with oneself. ... It does not matter what format you have recorded your diary. What matters is that you have recorded your thoughts and feelings at a moment in time.

E-mail today if you have kept a diary while recovering from, or caring for someone with, an eating disorder, to find out how you can contribute to *The Diary Healer*. I will e-mail you a selection of questions relating to chapters in the book. I look forward to hearing from you. Your voice counts.

(http://www.junealexander.com/2014/02/calling-diary-and-journal-writers-withexperience-of-an-eating-disorder/) 10 February 2014 (Alexander, 2014) (Appendix, *Calling Diary and Journal Writers with Experience of an Eating Disorder*) This blog entry led to 120 people responding. Next, a personal message of introduction and more details about the book concept were sent to each respondent. As well, each respondent was invited to complete an attached questionnaire on the process and meaningfulness of diary-writing while experiencing an eating disorder (Appendix, *The Diary Healer: Invitation to Contribute to New Book*). This step resulted in 70 people, who met the criteria of keeping a diary while experiencing an eating disorder, submitting diary entries. They became my cohort of research participants throughout the book creation project.

Primarily the research participants were people who had kept a personal diary while experiencing or having experienced significant eating disorders. Secondary participants comprised parents and other caregivers, and also researchers and health practitioners with expertise in the treatment of eating disorders. I was aware, from personal experience and the literature in the area (Broussard, 2005; Dayal et al., 2015; Rørtveit, Åström, & Severinsson, 2010) that these participants would express a range of anxieties, struggles, dilemmas and achievements. Examples included alexithymia, defined as the inability to put words to feelings and thereby make important distinctions between feelings; paralysing anxiety about making decisions; fear of food; fear of people's judgments; ego-dystonic symptoms such as a reluctance to access or accept treatment and ego-syntonic symptoms such as worrying about purging and weight loss because they are producing dizziness, muscle weakness, or hair loss (Alexander & Treasure, 2012; Nunn, Frampton, Fuglset, Törzsök-Sonnevend, & Lask, 2011; Roncero et al., 2013). See Chapter Three, for further explanation of these eating disorder symptoms,

which would require understanding, empathy and sensitivity in order to gain and maintain the trust and involvement of research participants experiencing this illness. Regular and transparent communication and interaction were vital in cultivating and maintaining trust. Candid sharing of my experience of diary-writing and illness was paramount in enabling the participants to identify with my story and feel sufficiently understood, connected and safe to share excerpts from their own diaries. From this base that was built on trust and transparency, deeply private stories emanated. While the narrator, I also was a participant and the participants were my equals in that their story was as important and worthy as my story. Acknowledgement and respect permeated every e-mail interaction and while each participant was an individual the level of trust was strengthened in knowing this also was a shared journey, with a community of 70 like-minded others, in which every voice would count.

## The Sourcing of Diary Excerpts

Having located participants, their diaries were of course the next important consideration. Creative practice-led research provided a method to explore the unsolicited diary's potential to increase understanding of the processes involved in disintegration and re-integration of body and identity when a person develops an eating disorder. Unsolicited diaries offered a methodological method that was less structured than other methodological approaches (C. Breathnach, 2016). Their open-ended, participant-driven nature lacked the inhibitions of defined boundaries like that, for instance, of questionnaires seeking data on specific areas such as satisfaction with health services. Unsolicited diaries also had potential to reveal perspectives of which the

researcher was not previously aware (Alaszewski, 2006a). Such diaries were my major research resource and drove the selection of content for the accompanying creative work. Study of the research participants' diary excerpts was supported through e-mailbased, open-ended questionnaires and questions to each participant. This procedure would help to retain the true context, intention of communication and translation, in taking what were essentially privately expressed thoughts and placing them in a public domain (Milligan et al., 2005). It also would help each participant to feel involved in, and part of, the research and book-creating process.

Important in the research method was the systematic approach applied in the sorting and selection of suitable diary excerpts. This phase was particularly informed and built on through the works of Charon, Schön, Brien and Pedgley.

## The Selection of Diary Excerpts

A continuous process of reflection in my respective roles of researcher, narrator and research participant assisted assessment on the relevance and fit of each research participant's diary excerpts for the book's aesthetics, information and coherence.

Diaries have many functions for their writers, including expression and communication; reflection, which increases self-knowledge; remembering; as well as recording experiences which may be positive, negative or seemingly mundane (Kenten, 2010); therefore, I attempted to ensure that diary excerpts were chosen to reflect this range, in addition to illuminating the private experience of developing and healing from an eating disorder. Personal diaries can cover every facet of the diarist's life; they can record not only the diarist's private thoughts and feelings, and struggle with illness and self-identity, but also daily events, influences and observations that add structure and meaning to their day. There is no time limit to the diary, apart from entries ceasing upon the diarist's death. As well, there is no limit to the length of a diary entry, depending on availability of pen and paper, as to how much the diarist might write on any particular day, at any moment.

Accordingly, I needed to decide what extracts from the diary entries to use, how much of the extracts to use, and where to use them. This process entailed reading through each entry, defining each with a coding system, making notes, integrating and allocating each to one or more themes in the book framework. This analytic approach drew on the grounded theory method described by Charmaz (1990) by enabling theoretical groupings to be developed from the data and analysing of relationships between the themes. This approach affirmed the traditional perception of diaries as a useful tool for recording and reconstructing events (Nicholl, 2010) and fostered an understanding of how each research participant constructed and perceived their world. The qualitative selection process involved categorizing excerpts under data headings that included illness behaviors and routines, living patterns and management of symptoms and recovery (Nicholl, 2010). This approach enabled data to be explored on the basis of repetition, and sourcing of additional data with open-ended questions until saturation point was reached. Engagement in a constant comparison method of coding and analysing data (Starks & Trinidad, 2007), enabled the most representative passages to be identified and incorporated in an ongoing process similar to that described by Broom et al. (2014). Progressively, the excess data was discarded. A next step involved

reflection on factors including validity, reliability, clarity and insight, and lucidness of expression compared with other entries in the same category, and deciding which to explore further (Kenten, 2010). Self-questioning was continuous in deciding which particular extract best expressed and represented shared experiences or emotions, as was constant checking to ensure the excerpts related directly to the book concept and research question. Reflection-in-action and on-action was ever present, for instance, in assessing the changes in expression of mood documented during the stages of the illness, the patterns of behaviour, and the effect of the illness on relationships and social interaction. A framework analysis approach discussed by Jones (2000), on using the unsolicited diary in qualitative research, enabled data to be systematically indexed, managed and evaluated on the basis of genuineness, credibility, representativeness and meaning. Constant checking and follow-up questioning with individual participants was undertaken to confirm correct context and interpretation of the data, and at times to invite further contemplation. My experience reflected that of Milligan (2005), who argued that diary techniques could offer new insights into health routines and coping strategies and uncover aspects that impacted on a person's wellness, and concurred with that of Jones (2000) and Snowden (2015) who posited that although often overlooked in qualitative methodology, the unsolicited diary had value as a social research method and data collection tool.

The approach of Charmaz (1990) to social analysis provided guidance in thematically and systematically reading and re-reading the data submissions. This part of the process involved seeking diary excerpts that best portrayed what I wished the

text to say, and confirming the extracts were placed in the correct context. In this way, analytical thought processes enabled recognition of the emergence of patterns and trends (Broom, Meurk, Adams, & Sibbritt, 2014). First person observations included the diary's usefulness, for instance, in the recognition and acknowledgement of early illness symptoms, in mapping of recovery efforts, in stepping down from health services, and in monitoring maintenance and relapse prevention strategies.

## **Ethical Conduct**

All research practice must do no harm. In this project, this priority was as important as the establishment and maintaining of trust. Trust between myself and the research participants was vital to not only allay anxiety, but also to possibly lead to more open revelations and sharing of diary material that could become rich sources of information for my book. My project gained ethical clearance through submission of a Negligible and Low Risk Review Process and Application Form to the Human Research Ethics Committee, which allocated the ethics project number: H14/12-257 (see Appendix, *Ethical Approval for Project*).

Measures were taken to honour ethical principles and ensure privacy and confidentiality of each research participant. Consent forms were signed not once but twice. Research participants had signed the first consent form before the work became part of a doctoral thesis. The second time occurred several months into the datagathering process when the work became part of the thesis. Maintenance of trust between self and each participant was a vital factor throughout the entire research and book-creating process, and I experienced nervousness when approaching participants

this second time, inviting consent on a form that now included not only myself as author but also a body of authority (Central Queensland University). In a noteworthy reflection of the trust established in the narrator-diarist and researcher-participant relationship, all original 70 participants proceeded to sign the second form. While anonymity was offered, with each participant invited to provide a pseudonym of their choice, most participants elected to be acknowledged with their true name, in stated defiance of the illness that their diary excerpts revealed had isolated them from their true or honest self and from mainstream life, in some instances, for decades.

#### Rigour

Besides meticulous scrutiny of the data, procedures were employed to uphold the integrity of the material provided in the diary excerpts and through subsequent e-mail correspondence with the research participants. The research term for this is rigour (Biggs & Büchler, 2007) which is described as:

... the strength of the chain of reasoning and that has to be judged in the context of the question and the answer, for example in the context of design as opposed to the context of physics or philosophy. (p. 68)

The sequence of steps undertaken to analyse information and data, and reach conclusions, comprised my practice-led method. The effectiveness of the method would determine the validity of the outcome, and whether it could be termed an insight or contribution to new knowledge and understanding. Records were compiled of all forms of communication, including diary excerpts, questionnaires, e-mail correspondence and,

in several instances, transcripts of recordings made during face-to-face meetings and on-line Skype interviews. As well, each research participant was included in the checking of the parts of their submissions selected for inclusion in the creative work. This process importantly allowed confirmation that the intention of, and meaning expressed within, each participant's diary excerpts and written narratives had been properly portrayed and placed in context in relation to their individual experience and collectively with contributions by research diary participants (Stake, 2008). This participatory approach also enabled the presentation and comparison of different perspectives on the illness and healing experience.

Returning of transcripts to participants for verification was one component for demonstrating the rigour of my research. A series of e-mail communications, outlining decisions in relation to the process of data collection, analysis and the strategies for developing the categories together with descriptions of the book creation process, aligned with the findings of Sandbergh (1997) in assisting the rigour and reliability of the approach (see Appendix, *Samples of Questions put to Researchers and Health Practitioners Working in the Eating Disorder Field*).

While my line of reasoning was based on relationship links between the research question, the context, the method, and the outcome of research, I also needed to consider how the rigour or strength of this reasoning would be judged. In approaching this challenge Niedderer and Roworth-Stokes (2007) was helpful in clarifying that research, objectivity, reliability, and validity were essential criteria for the rigorous conduct and dissemination of research, for example, Miles and Huberman (1994, p. 278)

and Black (1999, p. 35). Constant attention to honouring the criteria of objectivity, reliability and validity usefully qualified and enabled me to consider how practice could be applied in valid and rigorous ways in my research. Diaries in my project included but were not limited to those of self-analysis and self-guidance, observation, reflexivity and recording.

#### **Limitations and Strengths**

All studies have their limitations and in this project I was mindful that not all people who developed an eating disorder kept a diary and quite possibly the illness experience of such people could be different to those who did keep a diary. My project could represent only the experience that occurred within the project boundaries. For example, employment of the diary method meant that as the researcher, I relinquished part of the research process (Mackrill, 2008). Personal illness experience enabled me to have empathy and understanding for the stories shared in the diary excerpts but my research participants chose what passages from their diaries to share with me.

A limitation of my study format was the procedure for sourcing diary participants. All data gathering occurred on-line and this may have prevented responses from people who kept hard copy diaries but did not use the Internet. My respondents necessarily needed to be capable of writing a diary (Mackrill, 2008) and to have access to on-line communication. Also, habits of diarists differed: for instance, some were methodical, writing an entry daily, while others were more spasmodic. Some diarists used pen and paper while others preferred an on-line format. Some wrote poetry and others wrote prose. However, rather than be a limitation, such variations could be beneficial, adding

richness to the data through drawing on the unsolicited works of multiple diarists, of various ages, and over various time spans. Another limitation was the English language. The diary submissions were sourced globally and each participant needed to be able to communicate in English.

As volunteers, the research participants may not have been representative of the whole population of people with eating disorders. Nonetheless, their experiences were real, and importantly, the creative practice-led method afforded participants some control; they could choose responses and practice reflexivity themselves in sharing their diary excerpts with me. This process, of each research participant not only selecting the excerpts to share, but also providing reflections on why they chose these particular excerpts, added to the overall rigour and benefits of the practice-led research methodology. The methodological and theoretical flexibility of the diary approach accessed data that otherwise might have remained concealed (Mackrill, 2008). One revelation was poetry, a form of narrative expression that did not appeal to me but for which other research participants expressed a passion, leading to the insertion of an entire chapter on poetry in the creative work. Another revelation related to secrets. I had illness-related secrets and family secrets but had not intended to explore the subject in depth. However, data from participants emphasized secrets as a major theme and led to a dedicated chapter in the creative work. The experience of one diarist might be considered an isolated instance and be discounted, but a series of documented experiences, in these instances on poetry and secrets, by a number of diarists, aroused curiosity and encouraged investigation (Mackrill, 2008).

# Conclusion

This chapter has detailed the creative practice-led study design and explained the approach to the sourcing and selection of diary excerpts, approaches to maintain the safety and security of participants and the rigour and trustworthiness of the process. The method assists in answering the question: *How can diary excerpts be used in writing a book to assist people with eating disorders?* In the next chapter, I draw on my experience during each stage of creating this project, to present guidance for writers on the process of using diary entries to write a book.

# Chapter Three: The Process of Using Diary Entries to Write a Book to Assist People with Eating Disorders

## Introduction

The process of writing *The diary healer* took 36 months. I produced 93 000 words, and Routledge have published the work. Six months were absorbed in creating and refining the book concept, 24 months in research and data gathering, and writing of the text, and six months in the publication process. The prime focus at all times was the research question: *How can diary excerpts be used in writing a book to assist people with eating disorders*? In attending to issues and challenges that occurred during the book-writing process, five main themes emerged. These themes will be discussed in this chapter for the benefit of future writers seeking to use diaries in such work. The themes comprised: mapping the concept; gathering and melding the messages; securing trust; reflectively pursuing leads; and negotiating the narratives.

## Mapping the Concept

I suggested writing *The diary healer* to the London-based academic publisher, Routledge, in July 2013. I had written several clinical textbooks about eating disorders for this publisher but my memoir *A girl called Tim*, released by a mainstream publisher in Australia in 2011, was the main catalyst for this new book proposal.

Mapping the concept involved organising my thoughts with logic and clarity. I had four main topics to include: the diary, eating disorder, the patient's experience, and recovery. I had been unable to identify any books on eating disorders where excerpts from numerous personal diaries were the central theme. However, reader response to my memoir had affirmed the value of using diary excerpts in describing lived experience. As well, experts in the eating disorder field had found my story-telling techniques, in terms of illuminating the patient's experience, helpful in disseminating their research findings in medical textbooks and other forms of literature. Reflection on these factors led me to conclude that the patients' narrative, and particularly the personal diary, was largely overlooked as an information source, and unexplored as a self-help and therapeutic tool in the eating disorder field. I posited that if one story could be helpful in providing insight, more stories could be more helpful, and perhaps the personal diary experiences of others could be combined with mine.

I framed the book concept to focus on personal diaries of people with eating disorder experience portraying the book's message, and with professionals in the field providing background explanation. A 6 000-word book proposal was emailed to the publisher in August 2013. By now, the basic tenet of my practice-led inquiry was set. That is, my challenge was to source and transform diary excerpts from various diarists into a coherent and meaningful narrative to assist people with eating disorders. A review arranged by the publisher provided professional and scholarly feedback, and led to further refinement of the concept.

Taking a person-centred approach would be a very much less mainstream approach for an academic publisher. It was therefore a risk, but my professional and personal experience told me this book would work only by remaining true to my original idea of writing from the patients' perspective. Satisfied with my reasoning, Routledge

offered a book contract in January 2014, and the collection of diary excerpts began the following month, through a post on my website blog (see Appendix, *Invitation to Diarists to Share 'Evidence of Life Experience'*). This post outlined the book project and invited diarists with experience of an eating disorder to make contact. At this time I also enrolled in the doctoral program and gained ethical clearance to consider potential respondents as research participants and their diary excerpts as data. Participants were notified of these developments and were invited to sign a declaration of consent form granting permission to both CQUniversity and Routledge Mental Health to consider their submitted material for consideration for publication in both print and electronic format (see Appendix, *Samples of E-mail Correspondence to Diary Participants*).

I received many diary submissions via e-mail and these were collated into Word Document files and folders on my computer database, awaiting assessment. Establishing separate databases for participants and researchers helped to maintain focus on the book concept, and to keep a clear audit trail. With the diarists' data and literature review in hand, I proceeded to survey the material and investigate connections and gaps.

In this way, charting of the book concept continued. My task was to combine and chronicle the often similar but individually unique diarist experiences of eating disorders into one cohesive story. As someone with lengthy experience of the illness, I knew the complex challenges of recovery remained poorly understood, and the diary offered a novel approach to illuminate these issues. The book would survey concerns of bingeing and starving, and fixations with diet, weight and exercise that impacted on physical, mental and emotional health and on interpersonal relationships. Other issues would

include avoidance of social interaction; co-morbid illnesses such as anxiety and depression; and feelings of guilt, shame, stigma and worthlessness. Personal diaries presented a way to trace the deep-rooted fear that accompanied an eating disorder and the resultant disconnection between mind and self that evolved due to distrust of everyone and everything except the illness itself. Even the diary could become aligned with the illness and yet, the mapping would reveal, the diary also had the power to assist healing. As diary excerpts were received from participants I crosschecked their submissions against the facts and the literature on eating disorders, together with my own views on the challenges of eating disorders. This reflective procedure helped to ensure the scoping of the whole concept in my endeavour to provide insights on challenges facing people with eating disorders.

Reflection and discussion also took place with peers regarding dilemmas about focus. Such dialogue helped to define the limits involved in using an amalgam of voices to illustrate the diary's many facets in the non-linear process of developing and healing from an eating disorder. For example, a significant challenge, given the wealth of material in the diary submissions, was to decide what to include and omit. I knew from the review of the literature, my lived experience, and writing and advocacy work in the eating disorder field, that there were common struggles for individuals, families and therapists. Remembering my book would be written primarily through compilation and interpretation of diary entries helped to define what to explore and what to ignore. It would not be a clinical manual, or a treatment alternative. It would offer a tool for augmenting treatment, and facilitating self-awareness. It would demonstrate how, with

guidance, the diary could assist re-integration of a self that was honest in recovering from an eating disorder.

There are well known symptoms of an eating disorder, which affect both emotional and physical health, and include extreme emotions, attitudes, and behaviours surrounding weight and food issues. This information is available in the many memoirs and informative books already published. Little detail is provided, however, of the perplexing, frightening and frustrating aspects of this deeply personal struggle. My aim was to use the diary entries to portray this struggle and deliver central messages which included helping people with eating disorders to understand they were not alone in their struggle, they were not bad or weak, and they could develop new thought patterns and personal strengths to overcome the disorder. Therefore my mapping embraced the issues of self-stigma, self-shame, self-sabotage, hidden anxiety, fear and even terror, ambivalence about change, self-doubt, loss of courage, loss of hope, as well as the reemergence of hope, self-belief, self-honesty, and self-compassion. The ultimate aim in addressing these intrapsychic struggles was to help the person with an eating disorder, together with their family, friends and treatment team, better understand the challenges, and how to overcome them.

#### Gathering and Melding the Messages

The writing process involved the collection, selection and compilations of diary excerpts so that they would cover the concepts previously mapped and also cohere smoothly. Personal diary entries comprised the main source of material. Apart from my own diaries, I gathered excerpts on-line from the 70 diarists who had responded to the initial

blog invitations and subsequent questionnaires (see Appendix, *The Diary Healer: Invitation to Contribute to New Book*). The only prerequisite was that they had experienced an eating disorder at some point and had kept a diary for at least part of this time. The diarists lodged excerpts that they had photocopied, photographed or transcribed from their personal diaries, some of which were current and others were decades old.

Most excerpts came from traditional pen and paper diaries and 10 of the 70 diarists also lodged on-line diary entries from blogs, e-mails and apps. Twenty-nine of the 70 diarists also submitted poems. Overall, original material from 52 of the diarists was quoted directly or indirectly in the book. Some diarists shared one or two brief excerpts, describing part of their illness experience on one specific date, such as the day of hospital admission, while others shared thousands of words from diaries penned over many years, for example, encapsulating the struggles of accessing health services, getting a correct diagnosis, the treatment, recovery, relapse and interpersonal difficulties faced when re-entering the mainstream.

Decisions on what to include in the book were based on the ability of the entries to explain, elaborate, and illustrate the diary's recording of, and involvement in, the eating disorder. Entries were sought that would enlighten and connect with readers, and illustrate the experience of living with an eating disorder. A word search tool on my computer helped to locate relevant passages relating to specific themes across the hundreds of diary excerpts. For example, a search for the terms 'stigma' and 'shame'

located 20 excerpts. From these, phrases, sentences and paragraphs were selected and inserted as direct quotes or paraphrased to summarise the diary messages overall.

Other selections were based on the capacity to present a sequence of diary snapshots to portray aspects of the illness journey. For instance, some diarists started a diary in childhood due to feeling misunderstood, and their entries chronicled this and went on to record the development of their eating disorder through to diagnosis and recovery. Excerpts from each of these stages of the illness provided opportunity for the diarist's story, through their entries, to be woven into chapters throughout the book. In this way the diarists travelled through the book with me, and became part of the overall narrative. This technique, while tedious, contributed to the 25 chapters becoming a cohesive whole. It would have been easy to run a succession of each diarist's excerpts on each facet, but this would have created a stop-start effect, and I wanted fluidity to carry the reader forward in the narrative. By bringing the diarists together along on a narrative path that followed the illness experience, their stories, while individual, also at times became united, like a chorus, adding emphasis and providing a commonly shared but unique perspective, tone and insight to the eating disorder experience.

Narrative variety helped to link the diary entries and create the story. Poetry was an unexpected finding and, as a different form of diary expression, added colour and depth to the book. Besides the inclusion of a chapter on poetry, verses or several lines from a poem were inserted to start and conclude most chapters, as a technique to enrich the narrative. As well, professional insight into illness effects described in the diary excerpts was sought to help both the diarists and the book's readers increase their

understanding of the illness. I arranged meetings and interviews with experts, at international eating disorder research conferences (see Appendix, *Samples of Questions put to Researchers and Health Practitioners Working in the Eating Disorder Field*), and they subsequently lodged written contributions on-line. Selection of the professional contributions was based on adherence to the patient-centred narrative style and format of the book, and ability of the text to explain, for instance, why secrets occur when an eating disorder develops, how writing a diary could assist in developing trust, and how the diary could be a self-help tool in recovery.

Together with my own diaries, the data were reviewed, analysed, and considered for inclusion in *The diary healer*. Databases facilitated crosschecking and referencing, to avoid duplication, and to identify patterns in diary entries. Colour-coding and paragraph numbering helped to identify and analyse themes. In-depth reading, contemplation, and reflecting, were required as some participants sent e-mails containing thousands of words, and content was often intensely revealing and private. Whether or not the diarists lodged many words or only a few, each deserved due consideration in selecting and melding the material to addressing the question of how diary excerpts can be used in writing a book to assist people with eating disorders.

Flexibility in thinking assisted this phase of the book creation process. Reminders from a small circle of peers who volunteered as readers that text, whatever its format, had to include at least some traditional diary-writing elements, helped to surmount moments of indecision. Rigour in reflection as participant and observer, of the illness and the diary, assisted in resourcing and processing the large amounts of data. Such

practice also helped to maintain focus on the writing, editing and revision of the developing manuscript. Although keeping, elaborating, and otherwise working with a diary involved various forms of writing and even rewriting, this was *not* a book about the role of writing in the process of healing, for instance, which was a much larger topic. My challenge, while describing the eating disorder illness, was to constantly link the text to diary-writing techniques and elements. Assessing and selecting relevant data from the standpoint of participant and observer, and checking and rechecking with the diarists themselves that I understood the meaning and context of their words and the eating disorder language or voice, assisted this process. Through this transparent and collaborative approach, I hoped to define the unique qualities of a diary that facilitated recovery from an eating disorder.

#### Securing Trust

Securing of trust was integral to the creation of *The diary healer*. Belief in the need for the book had led to the mapping of the concept, a publishing contract and a cohort of research participants willing to entrust me with excerpts from their personal diaries, which until now had been kept strictly private. Trust was intrinsic to the relationship formed with the research participants, and in developing a narrative to inspire trust in readers. Throughout the project, I needed to create a sense of inclusiveness with each research participant so that they felt sufficiently safe, secure and at ease in sharing innermost thoughts and feelings. Clarity in what the diarists could expect in return for sharing deeply private material with me, for example, was crucial. My consistent message was that there was no certainty that their excerpts would be included in the

book; however, every contribution nevertheless would be considered and would contribute to the overall research. To offset possible disappointment, participants were invited to be included under their own name or pseudonym in the book's acknowledgement list. Securing trust with each diarist was an important element in the project's aim of reaching a target audience that comprised people who had experienced or were experiencing an eating disorder, and also those people who had yet to access health services.

Primarily for the ethical reason of providing identity protection, and to maintain an open line of communication, an e-mail address was the sole form of contact with each research participant. Without opportunity for face-to-face meetings, the development of an intimate level of trust required patience, empathy and understanding, to counter the known illness characteristics such as high sensitivity and difficulty in trusting others (see Appendix, *Example of Developing and Maintaining Trust, and Honouring Ethical Responsibilities, with Research Participant*). While I needed the participants to trust me, I also needed to trust them. This bond of trust was reciprocated and strengthened through the sharing process. We were all diarists with experience of an eating disorder who felt sufficiently secure to share deeply private material, and feelings of connection and belonging were strengthened through this mutual sharing of the illness experience. Diarists reported that their contribution to this book and research was providing them with a sense of self-worth and making their life count.

[T]hank you for the opportunity to share my story, ... and for giving me a voice that I have not had before and validating what I have been through to get where I am. (Ruby in Alexander, 2016, pp. 236–237)

Trust was procured through shared experience, supported with ethical clearance through the Human Research Ethics Committee, and in accordance with National Health and Medical Research Council guidelines. At all times, I was mindful of my research participants' distinctive vulnerabilities. I respected their right to withdraw from the project at any time, and emphasised that their wellbeing was highest priority. I nurtured their faith through identifying with their healing journey and through regular communication on the sometime complex processes in creating *The diary healer*, and by responding promptly to any query or indication of illness lapse.

Besides establishing a connection with the research participants, the development of a sense of trust with future readers was imperative for *The diary healer* to accomplish its aim of assisting people with eating disorders. Making the diarists the main voice in the first section in *The diary healer* was a technique undertaken to encourage trust among readers, by helping them to identify and engage with the content. The data gathering and melding processes had involved determining which diary entries of others and mine to publish—and to what extent. I had to trust my judgment in imposing limits on which and how much of my own voluminous entries to use, and make choices and set limits on which of my participants' entries to use, as did they in the first instance, in deciding what excerpts from their diaries to share with me. I needed to be mindful to not trust that the reader was as familiar as me or others cited

in the book with (a) the depths of hell offered by a severe, chronic eating disorder;(b) the challenges and ambivalent feelings associated with recovery; and (c) the rich and complex joys attendant to recovery.

The research participants were continuing to live their daily lives during the twoand-a-half years of the book creation process and were subject to both psychological and psychosocial challenges at vulnerable times. Several diarists relapsed and required hospital admissions. This posed the risk that they might experience anxiety and shame in revealing this setback in their healing process. There was also a risk that the reflection required in reading and sourcing excerpts from diaries, which had been written during a time of extreme mental and emotional duress, might trigger painful feelings and cause discomfort in the participant. These risks were reduced by establishing an early, strong bond of trust and respect between each participant and myself, so they felt at ease in sharing concerns and in seeking reassurance and clarification. Trust was nurtured and maintained through the rigour of providing empathy, respect and understanding; regular communication; prompt response to every e-mail; no pressure—participation was voluntary; collaborative decision-making; careful wording of every item of correspondence; encouragement of sharing with therapist/treatment team if any sign of 'triggering' occurred; and transparency at all times.

Sharing my story had helped to secure a firm base of trust. Research participants stated they felt connected and confident in sharing their story, *'because you have been there too; I know you understand'*. All remained involved in my project for its duration. At the outset, the participants stated they wanted to contribute data for the research

because sharing their story would help them feel their life counted. At the conclusion of the project they noted the process of reflection had led to an extra benefit, that of more clearly seeing their illness in the context of their life experience.

#### **Reflectively Pursuing Leads**

The diary entries told compelling stories of struggle and courage. I needed to identify with each story but remain sufficiently detached to maintain overall focus. I found it helpful here to integrate what I had learned from reading Schön, particularly relating to reflection in and on practice. My challenge was to locate leads and combine these leads, through paraphrasing and selected quotes, into one fluid text. To avoid feeling overwhelmed, for the databases had accumulated more than 300 000 words (approximately 1 000 pages double-spaced), I needed to be confident in absorbing testimonies that spoke to me and ignoring those that did not feel true to my instincts. Staying true to the research question at the heart of my book required constant selfsurveillance. Such rigour was necessary for writing a book whose themes originated from my own experience, intensely personal experience of others, and academic literature. Major leads included stigma, secrets and trust, sexual abuse, the influence of the Internet on diary formats, and poetry. These were not new leads, but the diaries presented their origin and impact in a new light. To address them I adopted a reflective process with self, other diarists, experts in the field and my manuscript readers.

My major themes for reference during practice of rigour comprised:

 A diary, in the context of my research limitations and focus, is a recording tool that can help the writer to connect with thoughts and feelings.

- 2. There are many ways of keeping a diary.
- 3. The essence of a diary is about being a friend with self but when you have an eating disorder, avoidance may kick in and lead to layers of secrets and deceit, not only with friends and family but also with the diary.
- 4. Secrets affect ability to be true or honest to self and to others and secrets, of which the diarist is not consciously aware, such as an eating disorder, can be particularly sinister. Here, the diary can provide a therapeutic bridge.
- A diary may become the basis for a memoir or other type of publication however there are many considerations.

A transparent and collaborative process, which involved reflection in my current diary, regular on-line correspondence with the diarists, face-to-face meetings and networking with academics in the field, and constant emailing with my manuscript readers, helped to ensure leads were thoroughly explored. Often, introductions and chance meetings at conferences—including encounters in lifts and during session breaks—or suggestions or key words followed up on the Internet, led to new perspectives and meaningful dialogues. For example, secrets were part of my illness for so long they seemed intrinsic to life, but discussion prompted the observation that secrets were a major issue, leading to a dedicated chapter, 'The role of secrets—how the diary can dupe you'. Stigma was another issue that seemed inseparable in the life of someone with an eating disorder. However, discussions helped me to see that diary excerpts could illustrate the effects of both public stigma and self-stigma, leading to the chapter, 'The many marks of stigma'. I delved beyond evidence recorded in the diary entries to develop an argument for diaries to be used as a form of sharing and thus a means of replacing the tendency for secrecy, self-shame, isolation and continued distress, with more self-affirming thoughts.

An alternatively objective and subjective approach, that is, considering standpoints in terms of both facts and feelings, helped to ensure comprehensive exploration of deep-seated factors. Some diarists observed that the reflective process of reading back over their diaries to select entries to share with me had helped them to see how far they had come in their recovery, and to see the illness more in context of their life rather than being their life. My manuscript readers, meanwhile, were helpful for contemplation of ideas during this frequent reflective, back-and-forward, writing process. An example was the poetry finding. I, personally, had not found refuge in poetry but it had been a helpful coping technique for other diarists. To incorporate a chapter to explore why some diarists found poetry useful necessitated the reassessment of other content and to make room for the poetry an early chapter on history was deleted.

Many submissions that I received from participants made it clear that their eating disorders formed around, and were built on, layers of secrets. This issue of secrecy has been explored in the literature, with contemporary articles including those of Zerbe (2016), Mustelin (2017) and Loeb (2010). It became apparent to me that secrecy, functioning as a form of avoidance and self-denial, was driven, in turn, by the complex ego-syntonic and ego-dystonic factors that create tension and internal ambivalence in many people with eating disorders. For example, an ego-syntonic

(calming and acceptable) thought 'I will try to take each meal as it comes and not overthink it' could be countered by an ego-dystonic thought (intrusive, difficult to resist), 'I must exercise for 10 minutes for each bite of food I take'. Moreover, selfgenerated thoughts that appeared to support healing, but in fact promoted secrecy, such as 'I ought not talk too much about my fears about food in case I cause concern in others' could also be reinforcing the eating disorder by delaying or even sabotaging recovery. The confusion between ego-dystonic and ego-syntonic symptoms may also be intensified by ever more complex and self-defeating patterns of ambivalence. For example, one might be reluctant to extricate oneself from an abusive romantic relationship because its traits, such as manipulation and domination, are aligned with and maintained by one's relationship with an eating disorder: 'If I end either or both relationships, I will have to face life without either or both relationships, and the emptiness that accompanies this thought is simply terrifying.' In these ways, secrecy is pivotal to sustaining an eating disorder, and awareness of its power is pivotal to change. Accordingly, I concluded that discussion on secrecy in the book might be useful in raising awareness in readers about the types of secrets that are helpful, and others that compound the illness.

Perhaps the most profound evidence of these secret thought challenges was revealed in the way entries chronicled the diarist's trust in the diary as a friend of self, but when the illness developed, the entries showed the diary inadvertently assisting disintegration of self by listing and emphasising the eating disorder's rules and demands. Thus, a diary can help to give voice to both constructive and destructive thoughts.

This insight is important for readers to appreciate and this is sometimes a painful process. Learning to distinguish between them by noticing one's own emerging feelings in the written word contained in a diary, rather than relying on the powerful, familiar and internal voice of the eating disorder, is vital. Consequently, I concluded that discussing these important nuances and processes in the book might be useful in raising awareness in readers about the advantages and disadvantages of keeping secrets while combating an illness that tends to be insidious in defining its own boundaries according to its own expanding set of rules.

Constant checking of the context of excerpts with diarists was important, not only in relation to secrets and trust, but also in exposing deeply entrenched beliefs that stemmed from traumatic experiences such as childhood sexual abuse or misdiagnosis of illness symptoms. My challenge was to tell the story through the diarists, balanced with insights from evidence-based research. To relate only the diarist's story could provide a powerful and sensational individual account, but possibly a misleading one generally. For instance, if one or more diarists had experienced sexual abuse, this did not necessarily mean most people with an eating disorder had experienced such abuse. Conversely, there were many people who experienced sexual abuse who did not proceed to develop an eating disorder. I aimed to be objective, balancing diary entries with current evidence-based findings, in a way that spoke primarily through the diarists.

Evidence of the impact of living with an eating disorder featured in each diary entry. My challenge was to retain the essence and portray the lead messages in these candid accounts and, concurrently, explore them through a lens of empirical knowledge.

The practice of reflectively pursuing leads required gathering, compiling, sifting and a re-gathering of the many parts that contributed to each topic, to produce a smooth flowing narrative. The guiding principal, always, was for the content to address how diary excerpts could be used in writing a book to assist people with eating disorders.

#### Negotiating the Narratives

Surveying piles of diaries and submitted diary excerpts, and wondering 'how can I write a book out of all this?' was a reminder that many factors require consideration in using diary entries to write a book. Negotiating the narratives required skills in flexibility, mindfulness, practice of rigour, techniques in presenting and monitoring the text and data, and maintaining communication with participants. A helpful first step was to contemplate why I wanted to share a participant's story, consider what was special about its form and theme compared with similar responses, and to decide how to effectively present the story in a way that honoured the integrity of the diarist.

While each diary participant had a powerful personal story to share, my focus had to be on those parts of their story that assisted in revealing the unique qualities of a diary that facilitated recovery and healing in the process of acknowledging, disengaging from, and moving beyond, an eating disorder. A secondary goal was to explore the connections between a diary and the power that may be found in constructing and expressing a larger narrative, for example, safely sharing the diary with a trusted therapist. At all times, mindfulness was required to integrate aspects of my professional knowledge, and personal experience, into selecting data for the project. These aspects comprised, as much as possible, the hot and cold running hell of eating disorders,

including dissociation from body, self, and others; the brave, creative, and inspirational people I had met and continued to meet on the pathway to recovery and beyond; and the various organisations and outlets for people's written expression.

Word document files stored in on-line folders assisted the research and book creation process. They included folders for patients, caregivers, therapists, on-line support groups and blogs, poems, acknowledgements, permission forms, excerpts sent to diarists, foreword and afterword, questionnaires, publisher, reader comments, book concept, manuscript drafts, and a folder for each of the 25 chapters in the book. Overall, this system worked effectively. No data was lost and the use of key search words, for example, fear, lonely, shame, obsession, hope and trust, helped to identify themes in diary entries and questionnaire responses. Next, colour-coding was applied to label each theme, and a numbering system helped to place them in an appropriate sequence. Crosschecking and cross-referencing of real names and pseudonyms in the correspondence, files and folders helped to ensure diary excerpts were attributed correctly (see Appendix, *Samples of E-mail Correspondence to Diary Participants*).

This seemingly simple process was useful in making selections and creating the narrative. However, flexibility was important. Sometimes, the unexpected occurred and diary entries produced revelations that altered the mapping of the concept—for example, an unexpected number of diary participants engaged in poetry writing, and the impact of layers of secrets was greater than anticipated. Reviews of early chapter drafts with my publishing editor and chief manuscript reader were helpful in refining text presentation and content. For instance, to improve narrative rhythm and flow, in

moving from one diarist's quote to the next, or from one reflection to the next, a solution was to paraphrase the excerpts from several diarists more neatly together, and call out their similarities and differences. Focusing on my research question, *'how can diary excerpts be used in writing a book to assist people with eating disorders?'* helped to direct the course of the story. In sourcing and selecting content for each chapter, a helpful technique was to consider: *What are my aims for this chapter?* and *What are the key points I hope readers will remember?* 

Conformity and adherence to style and formatting helped to avoid confusion over whose voice was 'speaking'. The paraphrasing and blending of excerpts from other diarists with my own was fairly straightforward, for we shared the mutually familiar 'language' or thought processes that were of the illness, and with that, a strong rapport. However, I was aware the reader might not have experience of diary-writing, or of an eating disorder, so care was necessary to present the narrative in a way that spoke to everyone. Solutions were found through asking questions, inviting re-submissions, and, sometimes, rejecting contributions. When I wanted to insert new text not planned in the original mapping, a helpful strategy was to write an explanation and justification for including it now. Although my focus was ever on the diary-as-healer, I also needed to keep focusing on whether this emphasis would be apparent and meaningful to the reader.

When finalising the content for *The diary healer*, I reflected on the entire manuscript with an analytical mind-set to ensure its entirety created something greater than the sum of the individual chapters or parts. Many re-writes had occurred. This

sifting process had enabled much of the daily repetition and drudgery that can occur in daily diary-writing to be deleted, and for patterns in the story to emerge. In writing a story based on diary entries, I had been mindful that this story would have a beginning and an end. A diarist, however, wrote about today with no certainty of what tomorrow would bring. My intense personal experiences with eating disorders, with diary-writing and with recovery, assisted in shaping this open-ended nature of diary-writing into a narrative. I could easily and sometimes emotionally (that is, personally) relate to what was revealed through other people's intensely intimate diary entries. However, my challenge was to think not about what I could relate to but what exactly, in those personal statements and testimonies, could contribute to an understanding of the potential roles of the diary in the healing process. As a bottom line, remembering that unless the text could be related or connected directly to the diary as a healer its deletion would have to be considered, was a helpful guide in negotiating the narratives.

## Conclusion

In addressing the research question: *How can diary excerpts be used in a book to assist people with eating disorders?* I understood, and empathised with, the 70 research participants because I had experienced the same illness. My main challenge was to let diary excerpts show how feelings can be understood more fully through repeated reading of, and reflection on, the written word. A secondary challenge was to present the excerpts in the context of a story that would enable the mainstream reader to understand and empathise with this experience. Transparency at all times was essential in this creative, practice-led research process of book creation. From this firm

foundation, the unknown challenge in resourcing, collating and drawing on diary entries to write a book became known; reciprocated trust led to important revelations and disclosures; and diary formats were explored and explained. This process that I created resulted in the writing of the creative work, *Using writing as a therapy for eating disorders—The diary healer*, and there were a number of insights, which form the basis of the next chapter.

# **Chapter Four: Insights**

#### Introduction

The Literature Review revealed no evidence of the personal diary being used as a resource with which to explore the experience of people who develop an eating disorder. My creative practice-led project, in which excerpts from personal diaries are used to write a book to assist people with eating disorders, begins to address this research gap. The diary, through its ability to record every aspect of the diarist's life, derives much of its effect and value from freedom for narrative expression and immediacy. In addition, each entry forms part of a linked series of daily snapshots of thoughts, feelings, and behaviours, which provides opportunity for later contemplation and reflection. This chapter discusses factors involved in using diary excerpts to write *The diary healer*. The factors include defining a diary entry; trust in writing and using the diary; the role of the diary in externalising the illness; and coming out and sharing publicly what has been a private story.

#### Writing a Date is All it Takes

A diary entry, a unique recording and reflection, can be defined by one main rule, that is, begin each entry with a date. A date provides authenticity. Unchangeable, it preserves and sets the scene for how the entry plays out over time. My research, however, exposes the need for another rule for diarists who are experiencing symptoms of an eating disorder. This second rule, beyond noting the date, is to make no rules. For a person with an eating disorder, rules create pressure and increase anxiety, and the feeling that enough is never enough. *The diary healer* illustrates this unease, with entries revealing how regimented daily rules for diet and exercise can strengthen and align with the eating disorder in isolating the diarist from a self that is honest. Most of the diarists in my project began writing a diary in childhood or adolescence, in attempting to fill an unmet and often times indefinable need. The mere act of writing the date seemed to say 'I am here today'. In times of uncertainty, for instance, the process of putting pen to paper, and writing the date, provided a tangible connection and feeling of continuity. There were no instructions on how to write a diary or why writing an entry might be helpful, and yet the boundaries and limitations were clear: an immediate, innate bond of trust and respect, and an unspoken and unquestionable acceptance of secrecy. Without understanding why, the one-to-one connection with a diary met a need for safety, privacy, comfort and a sense of belonging.

From a very young age, my thoughts and feelings had nowhere else to go except round and round in my head ... [T]he diary was quite simply the only outlet for describing, albeit for my eyes only, how I felt. (Renee in Alexander, 2016, p. 6)

To be a diarist the writer has only to record the date and start writing, about anything. Recording tools may comprise a pen and paper, a computer, a smart phone or other digital device. Some people write more when happy, others write more when feeling depressed or confused. Any time is a good time to write. Some people, unaccustomed to handwriting, feel more at ease writing e-mails, text messages, blog posts or using other forms of social media. These digital narratives can be copied, dated and stored in a Word file on the computer, or printed for storage and later reflection.

As well, a diary can be a depository for mementoes such as photographs, lists, maps, letters, greeting cards and invitations that add to the portrayal of the diarist's life at a particular time.

Writing the date helps to track the development and stages of illness, thus providing data that over time may assist in a correct diagnosis, treatment and re-entry into mainstream life. Through developing faith in a therapist and learning therapeutic writing skills and techniques, the diarist can use their diary to re-connect with their true self. For instance, instead of a place to create self-harming rules, the diary can provide a safe place to practise positive coping skills; to document experiences and reflect; to identify themes and how to respond to certain events; to set goals and problem-solve; to increase self-understanding and process emotions; to explore things unable to be discussed with others, and to identify connections between thoughts, feelings, and behaviours. Reflecting on entries that have a date enables a long-term perspective and during difficult times can provide reassurance that progress is being made.

Besides storing daily ramblings, observations and reflections, writing the date in the diary provides a practical self-monitoring use. The recording of medication dosages and treatment visits, and day-by-day emotional and physical side effects, present a more detailed picture to reflect on privately and to draw on in therapy sessions. In this way, the diarist can become a participant on the diarist's healthcare team, assisting in creating a tailored, patient-centred care plan. At stressful or momentous times between therapy sessions, diary-writing can assist as a self-mentor, providing a pause, for instance, by slowing illness thoughts sufficiently to avoid succumbing to an urge to

self-harm. Writing with abandon when feeling panic-stricken—for example, feeling an urge to self-harm due to a perceived criticism—can help to put thoughts and feelings in perspective, ultimately, until the diarist can think more rationally and feel at peace. In addition to providing in-the-moment relief, the series of dates creates a record that assists integration of self as time goes on:

I can look back 10 years and more and see who I was then, what I was going through, and the kind of person I was. The diary is an eternal record of my life. There are vital things I have been able to reference and process only through reading my diaries. If details of a trauma had not been written in my diaries I would have felt haunted for a long time since there are holes in my memory of the event. (Kristen in Alexander, 2016, p. 6)

Diary-writing is not an end unto itself, because the diary is a series of narratives. Each entry, fixed in time, is a record reflecting moods, feelings, insights, biases, and convictions on the date it is written. Each entry is individual but can link with others to reveal a wider view of the writer's reality, which cannot be changed but can be re-storied to provide guidance for today and tomorrow. Each new entry adds to the diarist's story that is as open-ended as life itself. The personal diary is potentially a great teacher and the challenge is to learn and apply its lessons. To start, writing the date is all it takes.

#### Trusting the Diary

Above all else, the diary became a trusted friend and secret depository to all the participants who shared their diaries with me. My responsibility as a writer was to respect and honour these intimate relationships evidenced between each diarist and diary, and maintain the essence in creating my story. The simple act of writing an entry may provide a lifeline in getting through the day, even when the entry serves to strengthen illness thoughts. When recovery begins and the diarist becomes aware their diary has been a chronicler of self-harming demands, and an orchestrator of the self-abuse that epitomises an eating disorder, the diary stands as a testimony to the suffering, helping the diarist to understand their illness experience and place it in the context of their life. As re-integration of mind and self begins, the diary continues as a place of trust, but now in a self-affirming way. The diary becomes a trusted power tool for the diarist to practice, explore, and debrief, in preparation for re-entering mainstream.

Trust in the diary is interwoven with secrets, which at times are crucial for survival. Some diarists contend that if they had openly shared thoughts and feelings that were not of their honest or true self, they would have been locked up due to perceived 'risk', or discharged from inpatient care for non-compliance, because they would be viewed as deliberately behaving 'badly' despite their illness causing such behaviour. Diaries become a refuge for describing painful and hellish instances of feeling misunderstood, disrespected, rejected, and alienated, when experiencing an eating disorder.

A major challenge in re-integration of mind and body is for the diarist to be able to trust their thoughts in writing the diary to enable honesty with self. Excerpts reveal that the illness trait of secret-keeping, which erodes trust, often originates in childhood. Issues pertaining to such deep-held secrets may emerge only through years of patient therapeutic guidance, due to multiple layers of suppression. For instance, whether or not a secret develops may depend on whether the diarist, at the time of experiencing abuse or trauma, feels safe enough in their environment to share details with another person. If shared, impact in the longer term may depend on adult response. For example, being told 'don't be silly' or 'you must have imagined that' may encourage emotional avoidance and distrust of adults, and the diary may appear as the only safe outlet. If the secret was never shared, the diary also remains the only confidant. In recovering from an eating disorder, however, layers of secrets like this need to be accessed, exposed and dealt with adequately, to foster trust in true self.

Trust enables the diarist to use the diary as a sounding board, for instance when contemplating reaching out for help for the first time. Diary entries may reveal the terror in defying the pull of the eating disorder. The diary may have been the only place fears have been released for years, with the diarist tussling with competing rational thoughts of self and irrational thoughts of illness, and now the diarist must override and break the long-held bond of secrecy with the diary, to seek help for the self-harming thoughts they cannot understand or control. Entries evidence intense fear and ambivalence. 'I accept I need to see a doctor, I break every rule I make and feel suicidal', is countered with 'I will cope alone; I just have to be more committed to my rules;

doctors will confirm I am terribly weak for not managing' and 'they might declare me insane, and lock me away from my children'. When a health service is eventually accessed, and an attempt is made to explain the problem, an incorrect diagnosis—'your bloods are fine, you look fine, you worry too much'—sends the diarist scuttling back to isolation, with their trusted diary their only safe release. When a referral to a specialist is made but delayed the diarist records 'See, if I were sick the referral would have arrived by now. I am disgusting and will cancel all doctor appointments'. However, sometimes in desperation, the diary itself may transition from secret-keeper to advocate and rescuer. Eve, through sharing her diary with a psychiatrist she had just met, began to receive care that would save her life:

From reading my diary he realised how sick I really was and made decisions that might have saved my life because of how suicidal I was. Later on when things weren't quite so desperate ... reading his words helped me to remember I wasn't alone and there were people who cared.

During acute hospital admissions, the diary continued its role of translator and informant:

It was great to have my psychiatrist read and challenge thoughts expressed there because during the week, until I saw him next, I was left with people I didn't trust.

The diary and my psychiatrist's next visit was all the hope I had to cling to.

Excerpts from Eve's diary (Alexander, 2016, pp. 169-170)

Trust in the diary assumes a heightened role in early recovery when the diarist faces grief and loss. This is the point at which the diarist becomes capable of understanding that the structures, rules and regulations that have been relied on to get through each day have been of their illness. For recovery to continue, the diarist faces the frightening reality that those structures and perceived support systems have to be abandoned and new thought structures need to be developed. In relation to the proana on-line community, this means that to recover the diarist has to let go of the eating disorder, and also sever a community that has seemingly understood and embraced them. For the traditional diarist, letting go of the deeply private, comforting but at the same time potentially harmful relationship with the eating disorder in the diary entails a level of grief akin to the perceived loss of a deeply intimate and secret friend. As a place of trust the diary is shown to provide a place in which to explore and come to terms with these losses.

Freedom for self-expression in making the diary entry, and deciding how the entry is used, is paramount to development and maintenance of trust. On-line diaries, which are readily accessible and enable openness, and immediate release and connection, seemingly confound the concept of the personal diary as a private and safe space and yet uphold other expectations of genuineness. Since on-line diarists can share entries immediately, their writing can be considered as true as possible to the moment. Blogging in a safely guarded, virtual village of like-minded people may encourage trust and self-healing, often in a cathartic way and, like the traditional diary, create a bigger picture through a linked series of entries over time. Diarists describe, for instance, their

experience of being drawn to a pro-ana site that offers acceptance but encourages competition and supports illness thoughts. Similar negative influence is evidenced within the privacy of the traditional diary, where the empty page beckons but the resultant entry may align with the illness instead of the diarist. Either way, even when a negative effect is at play, trust in the diary is maintained.

Today's diarist has a choice of formats, with the traditional diary offering room for quiet reflection and contemplation, and the on-line diary offering the ability for immediate interaction and communication. Essentially, whatever the recording method, a safe environment is required to allow the diarist to write unabated, free from judgment or criticism. From this base, with guidance, the diary can become central to the writer extending trust in the diary to trust in true self, and in others.

#### Using the Diary

For the writer, the study of a sequence of personal diary entries, from one diarist and more so from a number of diarists, can reveal patterns in the narrative from which leads can be pursued. Entries for my book project illustrate how, when an eating disorder develops, the diary is used as a survival and coping tool. They also reveal how, when recovery begins, the diary becomes a tool to separate self from the eating disorder, reintegrate mind and body and sustain on-going healing. Through all the illness stages, the diary documents the experience. At first it reflects the progression of disconnection taking place between the diarist's mind and body. Pages fill with rules, diet and exercise regimes, as the illness develops in and dominates the mind of the diarist. The pages also record attempts to ease the illness-driven anxiety and manage daily life by making

frequent fresh starts. Sometimes new entries, each with the hour and minute noted, are made several times on the same date. The inevitable breaking of the latest new rules is accompanied by guilt and shame, and fresh outpourings of self-hatred. In this way the diary evolves as both a coping tool and a self-harming tool.

The use of traditional and digital or on-line forms of diary-writing raises questions about whether the writing approach differs with one form or the other. For instance, an on-line diarist may feel more on guard about expressing their feelings, because they are aware others can read what they write and may respond in a critical way if thoughts reflect self-delusion, or the diarist may be more expressive on-line, because they know that through sharing in a supportive environment their concerns can be aired and tested, and reassurance and guidance can be given in developing a self that is honest. Questions like this led to reflection on the meaning and impact of the inherent diary elements of privacy and trust in using diary excerpts to write a book to assist people with eating disorders. A helpful technique is to constantly reflect on what each entry can contribute to the process of healing.

Some diarists use an offline diary for private reflections and engage in on-line diary-writing to share a selection of private thoughts with others. Perspectives offered by others can assist in identifying illness thoughts that engage in self-delusion and recognising and in developing new beliefs and perspectives with a self that is honest. Other times this process may cause fresh trauma to surface. Despite the risk of rejection or misunderstanding, diarists disclose that they find the routine of writing and sharing narrative formats, such as a blog, helpful in healing and restructuring their daily life. This

use of the diary is nothing new, but on-line diaries are innovative in enabling building and sustaining a sense of community with other diarists, and in allowing an immediate dissemination and exchange of writings with like-minded others. In this new context, the traditional role of confidant or confessor transitions from a diarist-diary relationship to a diarist sharing with immediate, often unknown, others. While on-line diary-sharing is active and even intimate in content, it also allows both the diarist and respondents to remain anonymous, if they choose, with true identities unknown to each other.

When using personal diary entries to write a book, rigour is required to avoid making incorrect generalisations. Each diarist is an individual and while their personal diary may reveal a riveting account of the effects of trauma, for example, this does not mean that all diarists who experience trauma will present the same outcome. This process of checking for patterns in the text illustrates the value in examining records from a number of diarists with similar experience. For instance, a diary entry may absorb thoughts and feelings that are too painful to verbalise or are buried in layers of secrets. An example is sexual abuse, which is a highly delicate and sensitive issue requiring more research in the field of eating disorders. Personal diary accounts provide a tool to help researchers investigate this area more fully. Stigma is another issue for which the diary is shown to provide the only source of solace. Defined as a 'mark' or 'brand' that signals disgrace and, at best, second-class status in a society, stigma emerges as a frequent theme in diary entries. Instances of public stigmatising and engagement in illness-driven self-stigmatising are revealed as a major issue. The marks of stigma, for a person with an eating disorder, can be layered, complicated, and deep

reaching, due to the illness characteristics and to societal and cultural influences. Entries reveal, however, that diary-keeping can assist in understanding how stigma is interwoven with secrets and shame and, with guidance, can provide an intervention tool to minimise its effects.

Using a diary to create a story for private use has value in the healing process of reflection, re-storying, and placing one's life in a larger, often revised context. Sharing one's story is an act and a statement that helps the writer take the big leap of standing up and saying 'I am not ashamed to say that I have had an eating disorder and I survived, and I am getting on with my life'. However when the diary is used as a resource for sharing a story publicly, such as *The diary healer* or a memoir, the unknown reader also deserves consideration. For instance, specific weights, or calories consumed, recorded in a private diary may serve as stark reminders of the diarist's suffering and struggle, and a deterrent in returning there, but in a story to be shared publicly, they may be read as unhelpful and 'triggering' for the broader audience. For someone experiencing ego-syntonic or ego-dystonic thoughts, and therefore unable to accurately perceive the severity of the illness, such works may also feel like a guide for developing and maintaining an eating disorder. The diary entries indicate that more research is needed into the use of story-telling and sharing in various stages of the illness.

#### Externalising the Illness

Identifying illness thoughts is an essential step in healing from an eating disorder. For example, a person experiencing an eating disorder may struggle with obsessive notions that enter the mind intrusively and cause guilt-laden thoughts such as 'I must do 500

push-ups before I eat that ice-cream' or a comment is perceived as a criticism, causing a binge to occur to suppress the painful emotion. Helping a patient to distinguish intrusive thoughts from healthy and productive thinking is an important therapeutic goal. The diary can help to do this, especially when it is used to trace and track evolving thoughts over time. Externalising the illness is a major concept put forward in narrative therapy. It is a conversational strategy designed to talk about the illness as separate from the person. Calling the illness 'the Eating Disorder', or 'Ed', helps to put psychological space between the person and the problem (White & Epston, 1990). The diary can be used as a tool to externalise and challenge the illness thoughts daily or more regularly.

Externalising the illness can help the diarist to start understanding that the thoughts, which have been causing them to self-harm and behave in unsociable ways, are not of their honest self. For example, the process of writing to release and externalise suppressed traumatic experience, can lead over time to the conscious repackaging of the traumatic experience in a manageable way, in the context of overall life experience, thus facilitating healing.

As discussed in various places in this dissertation, eating disorders may be ego-syntonic, which means the nature of the person plus illness is such that the person is unable to 'understand' or 'see' that she is ill. Indeed, a person with anorexia nervosa, for example, whose illness is ego-syntonic, may experience the symptoms as being helpful in managing daily stresses and reaching goals. From the perspective of significant others and potential healers this person is anosognosic, a neuropsychological term meaning unable (versus unwilling) to recognise their behaviours as 'disordered'.

The distinction between an ego-syntonic and an ego-dystonic illness means that memoirs—and thus diaries—occupy an uncertain and sometimes conflicted place in the imagination of the writer and the reader. What is being written and how it is being read depend on state of mind and stage of recovery.

The diary becomes a place to have a conversation with self, to analyse strategies and outcomes, and to look for patterns of behaviour that can be improved upon. For instance, when well into recovery, the diarist may observe: 'I missed lunch yesterday because the meeting went over time and now I feel guilty at the thought of eating lunch today. I am tempted to give it a miss. But I recognise this is an eating disorder thought that wants to harm me. I will eat my usual sandwich and call a friend straight afterwards to override the guilt.' Or the diarist may binge after an upsetting phone call and express self-annoyance and disappointment in their diary for succumbing to the eating disorder's pull. However, the process of writing about it enables the diarist to acknowledge that the bingeing has resulted from an eating disorder urge to numb emotional pain. Instead of feeling guilty and continuing to binge and self-harm, the diarist may note that next time such a phone call is scheduled, a coping strategy, such as a visit from an understanding friend, will be in place for self-care. In this way, the diary becomes a place to plan, prepare and debrief.

The ability of diary-writing to assist in distinguishing a self that was honest from the eating disorder is strengthened through reflecting on diary entries with trusted others. Diary participant Taylor explains:

Sometimes it would simply be a matter of writing down what ED was saying so I could take this to my treatment team so they could help me challenge the thoughts. Sometimes it would be a matter of reflecting on something that came up in therapy and realising how certain ED messages and behaviours were based in inaccurate self-perceptions. Mostly, journaling has been a way to help me and my own voice, more than learning to identify ED's voice. I needed to find my own voice to achieve and maintain recovery. Journaling through recovery has helped me learn to recognise when something I am mentally hearing or thinking is incongruent with my own voice, values, and way of being in the world. (Taylor in Alexander, 2016, p. 114)

Besides prose, other forms of narrative expression assist in externalising the illness. Many diarists, when experiencing ambivalence about their eating disorder ('is this me, or is this the illness?') find the writing of poetry a helpful coping technique and form of self-expression for establishing trust in self. They feel free and safe to share thoughts and feelings, and express concerns, by disguising them in verse, and releasing them in a veil of camouflage. Such poems allow the diarist to observe their situation from another perspective and to express emotions that otherwise might stay suppressed, for instance, relating to abuse or stigma. Persona poems are a way of detaching from the eating disorder to express, explore and understand its effects.

When deep in the throes of anorexia, poetry was the most accessible method of narrative expression for me. It allowed a creative space to explore with distance what I was trying to make sense of within ... This was incredibly validating and

provided a way to start articulating to others how I was travelling and what was going on. (Ellie in Alexander, 2016, p. 236)

Entries reveal how externalisation of feelings and thoughts, in prose and poetry, can assist the diarist in identifying components of the eating disorder and furthermore to proceed in emotionally processing and defining healthy elements of self.

### 'Coming Out'

In writing this book I assisted many people to move beyond using their diary as a private tool, to one that is used to share with other people in a way that they choose, and to reflect on as a record of their illness experience in the context of their life. The prime motivator in coming out and sharing a story recorded in a diary may originate in a desire to gain fresh perspective, understand self, and to be understood and believed in by others. As well, the diarist may believe that in sharing their story, they may help someone else, and in this way will make their suffering and their life more worthwhile. Timing, however, is all-important and sharing an illness story requires considerations for both writer and reader. For instance, the same story may impose fresh trauma, or inspire recovery in a reader, depending on the stage of their illness (Appendix, see Disclaimer). When the eating disorder dominates thoughts, the reader may be drawn to words and interpretations that strengthen the illness, and likewise when the voice of self is stronger, the reader may more easily notice words and interpret text in ways that encourage and affirm authenticity.

A revelation in the diary entries relates to the final stages of eating disorder recovery when grieving becomes an important part of the growth-into-a-hopeful-future process. One diary entry discussing grief may be dismissed as that person's individual experience, but when such experience is reflected in a majority of entries, in deep and graphic detail, it emerges as a major lead. Excerpts describe grieving for the 'life lost' during the illness, and grief in facing the loss of the relationship with the illness itself. The process of recovery, the entries demonstrate, involves more than behavioural observations, symptoms reduction, and clinical data and calculations. Recovery is also about emotions and feelings, including grief for the impact of the illness on relationships and education and career opportunities, and exploration of long-held self-beliefs and emerging new beliefs essential for coping in the mainstream. The insight into the effect of loss and grief illustrates the benefits of diary-keeping and, in writing a book using diary excerpts, the benefits of including a range of lived experiences, over a range of time.

The diary is revealed as a resource for story-sharing in private, for instance with known and trusted others, and in public, with unknown others. The Internet adds to the ways in which the diary can be written and used as a resource, and takes the definition of story-sharing to a new level. Easy digital access enables diarists to freely share candid thoughts and descriptions of daily life, minus the usual professional editing process that accompanies a formal publication, with an audience that is immediate and often unknown. Therefore, there is much to consider, including whether the writer's narrative is useful and revealing in the context of the current science, and whether the writer has

considered the ethical impact of releasing to an unknown audience their story, which necessarily is not only about their own life, but also that of close others. Everyone has been affected in some way during the illness experience. When undertaken with due consideration, the writing process can give opportunity and permission not only to the diarist but also close others to grieve, understand, forgive and develop self-love.

The process of sharing diaries to create *The diary healer* enables diarists to see that, even if patches of their life have been a bit messed-up, they have survived and come through. Story-sharing that draws on diary entries provides an opportunity to set the record straight, as the writer perceives it, and to help others understand the writer beyond what their eyes, or beliefs, have so far enabled them to see. In this respect, the diary is perhaps unsurpassed in its ability to help tell the writer's truth beyond their illness experience, and to offer a platform for reflection. Diversity in story-sharing, for instance from different genders, age groups, races, cultures and religions, may help to reduce the stigma, shame and stereotypical presentation of serious issues, and all readers can learn from, and be inspired by, stories of struggle and hope. Accordingly, with consideration to the many factors involved, the benefits of diary-keeping can extend from one to many.

While coming out can assist re-integration of self, the prime value of diarykeeping is in the way it can help the writer or reader understand their own self, and help them to communicate with self and others near to them. It may also increase selfconfidence and self-worth when shared and others respond favourably, but inner

healing is more important than an outward focus of trying to please or appease an audience.

Imagery is helpful in both healing and coming out. During the hard work of recovery, anticipation of coming out and sharing one's story may inspire survival and healing efforts. For example, the experience of imprisonment within the eating disorder can be likened to the life cycle of a cicada that spends a long time underground, in the dark, before emerging into the light with much song and dance. Such a story could be told from a dark place but it would be a story beholden to the eating disorder. Such a story would be angry, frustrated, chaotic and black. It would be everything the eating disorder is, and the diarist is not. For a positive story, inner healing has to occur before coming out. Therefore timing in story-telling, as noted, is of the essence.

The diary is testimony that the years lost to the illness are real; they are recorded; they have happened. They are gone. Reading diary entries and re-living the period of life incarcerated with an eating disorder is often agonising. However, the diary entries attest that coming out and sharing the part of self that has been confined to the diary, perhaps for years, can be cathartic, can lead to growth in self-belief, and facilitate the blending of mind and body as one.

#### Conclusion

The practice-led process of using personal diary excerpts to create the book, *The diary healer*, reveals the diary as a tool worthy of exploration in developing evidence-based, patient-centred support to address major issues. These issues include access to care, patient waiting time, step-up and step-down care, and service cost. Personal diary

entries show that with professional guidance, reflection on rules, for instance, made from one date to the next, can assist the re-integration and healing of self. Patterns of behaviour can be recognised through studying diary entries over time, and can facilitate increased self-awareness and self-understanding. Insights like this reveal the need for further research to build on the groundwork presented in this thesis and to create practical solutions—for instance, a diary-based resource to assist the processes of moving into and out of inpatient and outpatient eating disorder care environments. The next chapter, Chapter Five 'Conclusion', will present the summing up of this creative practice-led research project.

## Conclusion

This conclusion draws together the main elements and outcomes of my research, reflects on the publication of the creative work, and discusses options for utilising the findings to create further projects and research. The creative practice-led work, *The diary healer*, published in 2016, explored the process involved in using excerpts from personal diaries to write a non-fictional book to assist people with eating disorders. The practice-led research was concerned with the process of creating a book from diary entries and led to knowledge that provided functional meaning for that practice. The research, through putting forward knowledge within the practice of diary-writing in relation to eating disorders, led primarily to new understandings about the practice of diary-writing as an integral part of the book creation process. The research process demonstrated how diary-writing could provide a coping tool and healing tool when experiencing an eating disorder.

Significantly, the book-writing process presented a way to explore and assess how diary-writing could be applied as a method of private self-help, and as a therapeutic tool in healthcare environments. Excerpts shared from personal diaries provided a means for exploring the private thoughts and feelings of multiple people experiencing an eating disorder, and for using this deeply intimate material to write a book. Demonstrating that the diary could be used in this way was important because, while the diary had been discussed quite a lot in the eating disorder field, to my knowledge this project was the first to use multiple personal diaries to explore how diary excerpts could be used in writing a book to assist people with eating disorders. Furthermore, the project indicated diary excerpts were a useful means for presenting evidence of life experience; for example, excerpts illustrated the in-the-moment confusion and thought disruption that occurred between the body and identity when an eating disorder developed. The excerpts also presented a way to reveal and clarify epiphanies that became healing points. This sharing of confidential, person-centred information enabled the creation of a narrative illustrating the diary-writing process of documenting re-integration, reflection and facilitation of change within self. The creative writing process also provided insight into making decisions in relation to mapping the book structure, content, variation in narrative expression, and selection and placement of diary excerpts.

Examination of diary excerpts in the light of established literature was an important step in creating an interesting non-fiction story that supported self-discovery and renewal. The process of writing *The diary healer* demonstrated how application of diary-writing techniques and skills could contribute to understanding of self and the body, and re-integration of a self that was honest. Significantly, the creative work produced a resource to raise awareness and facilitate use of diary-writing in the healthcare environment. Records of diarist experiences of therapeutic techniques contributed to the literature on the likely benefits and limitations of utilising the diary as a self-help and collaborative healing method.

The research extrapolated on the writing process of using diary excerpts. It is important to note this art-based research did not prove utility or effectiveness. Rather,

it explained why a creative writing piece was compelling, and why it might reveal nuances of a human experience, in this instance eating disorders, in more detailed ways. The diarist might describe, for example, illness symptoms as being helpful in managing daily stresses and yet be incapable of recognising such thoughts or behaviours as unusual. The effective illustration of this experience through diary excerpts was significant in the book-writing process because it demonstrated how text could be read and interpreted differently, that is, through illness-driven thoughts or self-driven thoughts, depending on state of mind and recovery stage. Influences were shown to relate to the level of ego-syntonic and ego-dystonic thoughts, and the research project indicated that diary excerpts provided a significant means for exploring this complicated ambivalence.

The identification of secrets as a major theme in the diary excerpts, and the ways in which diarists addressed secret-keeping, self-denial and shame, both literally and figuratively, indicated that the process of diary-writing could reveal deep insights that seemed unattainable in other ways into the illness experience. For example, the data indicated sexual abuse was a highly delicate and sensitive issue, and diary excerpts could provide powerful and sensational individual accounts. However, to relate only these stories without placing them in the wider context of established literature could be misleading, generally. If one or more diarists have experienced sexual abuse, this does not necessarily mean that most people with an eating disorder have experienced such abuse. Conversely, many people who have experienced sexual abuse do not proceed to develop an eating disorder. Personal diary accounts provide a tool to help

researchers investigate this area more fully. Established literature was found to be scant, exposing a need for deeper investigation of the impact of different forms of abuse in the development of eating disorders.

The research data indicated that diary excerpts could be incorporated into a book in a way that revealed details about the eating disorder experience in a first person way. The data also suggested that diary-writing could be unhelpful as well as helpful, indicating a need for more research on the use of the diary in-person-centred and self-help health care. Of particular concern was the revelation that the diary, without therapeutic guidance, was susceptible to uses that aligned with and strengthened the illness traits and, consequently, hindered efforts by the diarist to recover and heal. Notably, however, even when illness thoughts dominated diary entries, the research participants observed that their personal diary-writing had been helpful as a survival and coping tool, and a significant number considered the practice of writing as having a major role in healing from their eating disorder. This research finding raised the question whether professional guidance and mentoring in diary-writing could accelerate the healing process. This point was important because the Literature Review uncovered no evidence of this particular application of the diary in therapeutic settings. Some diarists confirmed they shared their diary or parts of entries with their therapist and it became a useful, collaborative engagement tool. For instance, the patient wrote an entry in their diary, either with pen and paper or on-line, and the therapist responded by writing between the lines of the paper diary, sometimes in different coloured pens, or in digital format such as e-mail or messaging, to intervene, guide and

support the diarist in recognising, confronting and dispelling illness thoughts as they arose. Evidence such as this merited further investigation, for example, on whether the style and format of text made a difference in helping the diarist to determine which thoughts were honest and which were of the illness. Determination of whether on-line diary-like writing formats supported on-going recovery and re-immersion in mainstream life as effectively, or more effectively than the more private pen-and-paper diary, also was worthy of further consideration, but was beyond the scope of this investigation.

Throughout the investigation into how personal diary excerpts could be used in writing a book to assist people with eating disorders, the intention was to create a story that illustrated the diary's possible contribution in integrating body with self. The use of diary excerpts as the main voice in the creative work was a vital element in achieving this aim. This process, besides enabling each diarist participant to feel they were respectfully understood, assisted depiction of the depth of daily challenges encountered in surviving and healing from this most serious of all mental illnesses. Through enabling diarists with an eating disorder to express their innermost voice and release their evidence of lived experience, *The diary healer* portrayed how diary-writing might assist and encourage the healing process. The personal diary was shown to be a potentially useful tool for the writer to develop self-awareness and to move from an inward place of isolation and secrecy to sharing in a safe and supportive environment, as a step towards adjusting to and re-engaging in mainstream life.

The research illustrated how the diary, through its ability to document on every aspect of life, differed from other narrative forms by deriving much of its effect from its

immediacy and open-endedness; in contrast, a memoir, for example, gave a reflective account of a diary's contents, over a defined period, at a later stage. Personal diaries were shown to provide an appropriate method and phenomenon of inquiry in portraying the process of disconnection and re-connection when developing, and recovering from, an eating disorder. The diaries offered an opportunity to study each research participant's experience of the illness over time, and to relate their experience to the social and cultural context of the time. They allowed individual experiences to be compared, and patterns and differences to be observed and reflected upon. However, not all revelations that occurred during the creative-led process were included in the project. At times the temptation to include them was strong, but when the back and forth process of reflective practice revealed insufficient connection to the research question, they had to be set aside. For example, a diarist late in the research project shared graphic details of her healing story, which included a chronological sequence of body tattoos. Her diary was not in a book but embedded on her skin. Finding no research in this area, experts in the eating disorder field were consulted. The consensus was that the topic of tattoos and eating disorder recovery was interesting, and the tattoo narrative indicated an intriguing find. However, the back and forth reflective process concluded that exploration would be required, the word count was already high and the tattoo investigation would have to wait.

The project noted an increasing emphasis in the literature on the potential of the diary as a component in on-line healing tools in the treatment and prevention of eating disorders. However, there was wide agreement that more high quality research was

needed to clarify the role of e-health as an intervention tool in health care delivery systems. The comparative lack of evidence-based studies across the board on uses of the Internet was failing to halt a proliferation of on-line tools that appealed to health care providers and consumers seeking accessible and affordable solutions. While this area of research was outside the scope of my project, the creative work contributed to this on-going discussion.

My project contributes to the expanding field of scholarly works that recognise patients and service users as a rich source of healthcare-related stories that could lead to improvement in clinical outcomes and practice (King et al., 2006). Established literature reveals the diary as a tool with which to address major issues including ease of access to care, patient waiting time, and service cost. Patients are becoming more resourceful and expectant of collaborative care. The importance of patients being a participant in their own recovery is being recognised more in the eating disorder field (Dawson et al., 2014b). This increases impetus to include patient stories, for which diary excerpts provide an important resource, in both therapy and health practitioner education. To extend this line of research I plan to assess how The diary healer can be best used as a therapeutic tool. For example, a project to compare diary writing with and without therapeutic intervention may provide a useful method of evaluating the effect of diary-writing as a therapeutic tool in the treatment of eating disorders, and a means of advancing knowledge and understanding in the patient-centred recovery model. Such research could assist the establishment of a toolkit as a companion resource to teach and guide health practitioners and writing professionals in applying

*The diary healer's* techniques in a range of therapeutic contexts. Since the release of the book in mid-2016, I have designed and launched a new website http://www.thediaryhealer.com to share my project's findings and support my mental health advocacy and writing work. My research provides a resource in my roles as a representative of patients and caregivers on international and national government and non-government healthcare and educational institutions and working groups. International and national conference presentations and peer reviewed journal article submissions, relating to the use of the diary, also are providing opportunity for constructive feedback on the value of diary therapy in healthcare training and in provision of treatment.

I recognise that my creative practice-led project, while presenting several significant findings, is only an in-depth study into a very small aspect of the eating disorder and literature fields. Accordingly, I appreciate the limitations defined by the possible scope, the methodological restrictions and practical realities. The creative work primarily is about the process and utilisation of diary-writing. Although keeping and otherwise working with a diary involves various forms of writing and even rewriting, this book is not about the role of writing in the healing process, which is a much larger subject. Not all people who develop an eating disorder keep a diary and my project can represent only the experiences that occurred within the project boundaries. Another limitation is that the procedure for sourcing diary participants occurred on-line and this may have prevented responses from people who kept pen-and-paper diaries but did not use the Internet. My respondents necessarily needed to have access to on-line

communication. Also, diarists did not have uniform habits. Beyond the obligatory noting of the date, some were methodical, making daily entries, while others were spasmodic. Some diarists used pen and paper while others preferred an on-line format. Whether on-line diary-like writing and sharing formats were as effective or more effective than pen-and-paper diary-writing was worthy of deep consideration but beyond the scope of this investigation. Some diarists wrote poetry and others wrote prose. Exploration of why some diarists were drawn to poetry and not to artwork or music, or another creative pursuit, also was deemed outside the boundaries of this investigation.

However, while acknowledging these limitations, it is important to note that in other respects, variations of backgrounds and behaviours among participants could be beneficial, adding richness to the data, through enabling access to unsolicited works of multiple diarists, of various ages, and over a range of time spans. Another limitation was the English language. The diary submissions were sourced globally and each participant needed to be able to communicate in English. Eating disorders do not discriminate on culture or language and therefore the research participants may not have been representative of the whole population of people with eating disorders. Nonetheless, their experiences were real and, importantly, the creative practice-led method afforded participants some control; they could choose responses and practice reflexivity themselves in sharing their diary excerpts for the research project. This process of each research participant not only choosing the excerpts to share, but also providing reflections on why they chose particular excerpts, added to the overall rigour and benefits of the practice-led research methodology.

The creative project presents new possibilities regarding scholarly aspects in the eating disorder field, where established literature reveals a paucity of findings on causes and lack of consensus on solutions for treating the illness. In the narrative field, multiple personal diaries have been rarely used to present the main voice of a text. Therefore *The diary healer* demonstrates, and at the same time helps to address, a significant gap in the literature in relation to the use of personal diaries as a data source for writers.

The project opens up new questions for addressing in further research and future work. For instance, does the process of diary-writing, with guidance by a person with expertise in the narrative, assist re-connection between the body and self/identity? The project provides a foundation for more research into the use of diary-writing as a healing tool and creative writing method. It provides a base from which to explore and develop diary-writing techniques that assist healing; to create a set of tools for addressing the complexities involved in healing the wounded self; and to nurture the development of a healthy relationship with self and others. A major learning point has been that metaphoric terms like 'authentic self' may be confusing for the reader. Therefore, the intent of drawing on diary examples that help a reader to notice and distinguish disordered thinking from rational thought will be more fully realised in a second edition of The diary healer. The second edition will avoid jargon and metaphorical language that might confuse the reader, or unhelpfully reinforce black and white or delusional thinking, and will undertake greater investigation of ego-syntonic and ego-dystonic thought processes from the perspective of individuals affected by an eating disorder. The revelation that writers utilise persona poems as a means for

detaching from their illness, to explore and examine its effects, also warrants further examination. The research project establishes a foundation from which to address and establish an evidence base for another research question: *Can diary-writing direct and develop (and heal) the (dis)integration of the body and self/identity when an eating disorder develops, and facilitate a readiness for healing?* 

The practice-led research project necessitated a complex, backward and forward interaction between the practice of writing about illness experience and the theoretical structure of the creative work. It required consideration of the potential and ability of each component in the creative practice and exegetical research framework to generate knowledge, and therefore cultivate new perceptions and awareness. The practice-led approach elucidated the eating disorder experience through personal diary excerpts while acknowledging and respecting the need for contextual understanding. It encompassed both the practice and the exegesis and recognised other research paradigms. The research innovations were revealed more in the differences of the practice and the research question than assuming, for instance, compatibility between the two. The diary healer is not a clinical manual, or a treatment alternative. It is an example of how the diary can be a useful tool. The integration and use of diary excerpts reveals possibilities for employing the diary as a means for communicating with self and others, for augmenting treatment, and facilitating self-awareness. Through compilation of diary excerpts, *The diary healer* demonstrates how, with guidance, the process of diary-writing can influence and assist the process of re-integration of self in recovering from an eating disorder. This project will be helpful to authors wishing to initiate and

apply diary extracts as part of non-fictional narratives or other literary works. It illustrates the technique of combining diary excerpts with academic knowledge to create a literary work that offers fresh perspectives on the usefulness of the diary. Evidence is presented in a way that encourages the reader to reflect and to reach his or her own conclusion to the question: *How can diary excerpts be used in writing a book to assist people with eating disorders?* 

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## Appendix A

## **Ethical Approval for Project**



Secretary, Human Research Ethics Committee Ph.: 07 4923 2603 Fax: 07 4923

2600 E-mail: ethics@cqu.edu.au

Prof Margaret McAllister and Ms June Alexander School of Nursing and

Midwifery

Dear Prof McAllister and Ms Alexander

12 December 2014

#### Appendix B

#### Human Research Ethics Committee Ethical Approval Project: H14/12-257

Using diary-writing as a resource in the therapeutic context, comprising: 1) the creative work titled using writing as a therapy for eating disorders—the diary healer, and 2) an exegesis exploring the question: how can diary-writing connect the body with the self?

The Human Research Ethics Committee is an approved institutional ethics committee constituted in accord with guidelines formulated by the National Health and Medical Research Council (NHMRC) and governed by policies and procedures consistent with principles as contained in publications such as the joint Universities Australia and NHMRC *Australian Code for the Responsible Conduct of Research.* This is available at http://www.nhmrc.gov.au/publications/synopses/\_files/r39.pdf.

On 12 December 2014, the Chair of the Human Research Ethics Committee considered your application under the Low Risk Review Process. This letter confirms that your project has been granted approval under this process, pending ratification by the full committee at its February 2014 meeting.

The period of ethics approval will be from 12 December 2014 to 30 June 2015. The approval number is H14/12-257; please quote this number in all dealings with the Committee. HREC wishes you well with the undertaking of the project and looks forward to receiving the final report. The standard conditions of approval for this research project are that:

- you conduct the research project strictly in accordance with the proposal submitted and granted ethics approval, including any amendments required to be made to the proposal by the Human Research Ethics Committee;
- 7. you advise the Human Research Ethics Committee (e-mail ethics@cqu.edu.au) immediately if any complaints are made, or expressions of concern are raised, or any other issue in relation to the project which may warrant review of ethics approval of the project. (A written report detailing the adverse occurrence or unforeseen event must be submitted to the Committee Chair within one working day after the event.);
- you make submission to the Human Research Ethics Committee for approval of any proposed variations or modifications to the approved project before making any such changes;
- 9. you provide the Human Research Ethics Committee with a written "Annual Report" on each anniversary date of approval (for projects of greater than 12 months) and "Final Report" by no later than one (1) month after the approval expiry date. (Forms may be downloaded from the Office of Research Moodle site—http://moodle.cqu.edu.au/mod/book/ view.php?id=334905&chapterid=17791.);
- 10. you accept that the Human Research Ethics Committee reserves the right to conduct scheduled or random inspections to confirm that the project is being conducted in accordance to its approval. Inspections may include

asking questions of the research team, inspecting all consent documents and records and being guided through any physical experiments associated with the project;

- 11. if the research project is discontinued, you advise the Committee in writing within five (5) working days of the discontinuation;
- a copy of the Statement of Findings is provided to the Human Research Ethics Committee when it is forwarded to participants.

Please note that failure to comply with the conditions of approval and the *National Statement on Ethical Conduct in Human Research* may result in withdrawal of approval for the project.

You are required to advise the Secretary in writing within five (5) working days if this project does not proceed for any reason. In the event that you require an extension of ethics approval for this project, please make written application in advance of the end- date of this approval. The research cannot continue beyond the end-date of approval unless the Committee has granted an extension of ethics approval. Extensions of approval cannot be granted retrospectively. Should you need an extension but not apply for this before the end-date of the approval then a full new application for approval must be submitted to the Secretary for the Committee to consider.

The Human Research Ethics Committee wishes to support researchers in achieving positive research outcomes. If you have issues where the Human Research Ethics Committee may be of assistance or have any queries in relation to this approval please do not hesitate to contact the Secretary, Sue Evans or myself. Yours sincerely,

Dr Tania Signal Chair, Human Research Ethics Committee

Cc: Professor Donna Lee Brien (co-supervisor) Project file



Approved

## Appendix C

## **Declaration of Consent**

I, the undersigned, grant permission for:

**CQUniversity** and **Routledge Mental Health** and their licensees to publish, both in print and electronic format, and in all languages, the following materials pertaining to myself in the forthcoming publication and work:

Using Writing as a Therapy for Eating Disorders by June Alexander

PhD in Creative Writing by June Alexander

Material to be used: E-mail response to questionnaire

Tick one of the following two options; if you select the second option, be sure to insert your pseudonym—for uniformity throughout book, pseudonyms are limited to

first name only.

- 1.  $\Box$  I agree to have the material published with my name attached.
- 2. □ I would like the material to be published without my name attached and the author/editor and the publisher to make every attempt to ensure my anonymity. I understand, however, that complete anonymity cannot be guaranteed and it is possible that, for example, someone who looked after me, or a relative, may identify me.
- 3. D My pseudonym is (please choose first name only):

I understand that while I am at liberty to revoke my consent and have

material pertaining to me removed at a reasonable time prior to publication, this is not

possible once publication has taken place.

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

Name and address (postal and e-mail):

Website: http: www.junealexander.com

E-mail: june@junealexander.com

## Appendix D

#### Disclaimer

Everyone has a story to tell. No two stories or lives are exactly the same. The way we see our life may be entirely different from another's perspective of us. Sharing different perspectives, telling our stories, and reading the stories of others helps us to see fresh possibilities. While *The Diary Healer* is meant to encourage, comfort and inspire, it may also trigger painful memories or challenging emotions. Care has been taken to avoid triggers without compromising the reality and authenticity of the many participants who share their healing journey. It's important to remember, however, that eating disorders and distorted eating can be experienced differently in both physical and behavioural ways. This book shares many stories and, as you travel through, you may find you relate more to parts of one story than parts of another. Self-care as you read, pace yourself and make time to reflect on your own healing journey. Like everyone in this book, you have your own story and if any part makes you feel 'triggered', that is, if you struggle emotionally in any way, talk about it to someone you trust and get help. Oh, and keep writing because as this book reveals, keeping a diary can help your healing process.

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## Appendix E

#### **Communication with Diarists**

## Initial Blog Invitation to Diarists with Experience of an Eating Disorder Calling Diary and Journal Writers with Experience of an Eating Disorder

February 10, 2014

Hop on board a new literary adventure by sharing excerpts of your diary-writing in a book to be called *The Diary Healer*. In this book I am setting out to demonstrate how writing a diary or journal can help us understand, inspire, heal and liberate our self and at the same time provide a tool to educate others—such the health profession—on what the inside story of an eating disorder, what living with this illness, is really like.

The Diary Healer—Using Writing as a Resource to Treat Eating Disorders (the working title), to be published by Routledge (London) provides an opportunity to share your 'evidence of life experience' to educate and help others.

Amazingly, sadly, the process of diary-writing remains a largely untapped resource in health care professions, in helping people to heal and 'know who they are' at every life stage, and evidence-based research particularly in the field of eating disorders, is sadly lacking. This book aims to inspire correction to this imbalance.

Diary-writing is particularly helpful in helping us to understand who we are, and cope with challenges such as mental or physical illness, emotional pain and trauma. *The Diary Healer* will draw on diary-writing and eating disorder experience, together with evidence-based research, to explain why and how the process of diary-writing can assist in recovery and in maximising life quality and potential. While this book's primary healing focus is on eating disorders, it offers guidance for all who seek to be more in touch and in tune with their true self.

#### Getting in touch

*The Diary Healer* will show how writing about our life, especially what we consider the important issues, can increase our self-awareness and help others to understand us. It will show how writing can help us to get in touch with who we really are, and to define our place and purpose in our personal relationships, in our family and workplace, and in the world.

Writing a diary can help us feel understood when 'nobody out there' seems to care, and when 'everybody out there' seems to think we are a bit loony; writing a diary can help us feel safe, when the outer world seems to be full of pot-holes. Writing a diary can help us define and separate our self from the eating disorder.

#### Sharing a moment in time

I welcome interest particularly from people who have had, or have, an eating disorder, and also caregivers (families, partners, siblings) and health professionals (clinicians, therapists, social workers) who have found journaling or diary-writing a comfort and an effective way to sort feelings and thoughts, to debrief and connect with oneself. You might be 20 years old or 90 years old, your diary may cover a week or 50 years, it does not matter. You might have recorded your thoughts and feelings with notebook and pen, on a laptop, or Smartphone App. It does not matter what format you have recorded your diary. What matters is that you have recorded your thoughts and feelings at a moment in time.

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## E-mail today

If you have kept a diary while recovering from, or caring for someone with, an eating disorder, e-mail: june@junealexander.com to find out how you can contribute to *The Diary Healer*. I will e-mail you a selection of questions relating to chapters in the book. I look forward to hearing from you. Your voice counts. Hurry along, as the manuscript deadline is August this year.

This entry was written by June, posted on 10/02/2014 at 9:52 pm, filed under <u>Books</u>, <u>Eating</u> <u>Disorders</u>, <u>Issues</u>, <u>Life Writing</u> and tagged <u>diary</u>, <u>Diary Healer</u>, <u>Eating Disorders</u>, <u>E-mail Today</u>, <u>research</u>, <u>The Diary Healer</u>. Bookmark the <u>permalink</u>. Follow any comments here with the <u>RSS feed for this post</u>. Both comments and trackbacks are currently closed. <u>Edit</u>.

#### The Diary Healer: Invitation to Contribute to New Book

#### Invitation to Diarists to Share 'Evidence of Life Experience'

The Diary Healer explores how the diary can help understand, inspire, heal and liberate self and provide a learning tool for others.

Writing about our life, especially the important issues, can help us to better understand these issues and eventually diagnose problems that stem from them.

Yet the process of diary-writing remains a largely untapped resource in health care professions, in helping people to heal and 'know who they are' at every life stage, and evidence-based research particularly in the field of eating disorders, is sadly lacking. This book aims to inspire correction to this imbalance.

Diary-writing is particularly helpful in helping us to understand who we are, and cope with challenges such as mental or physical illness, emotional pain and trauma. In *The Diary Healer* I draw on diary-writing and eating disorder experience, together with evidence-based research, to explain why and how the process of diary-writing can assist in recovery and in maximising life quality and potential. While this book's primary healing focus is on eating disorders, it offers guidance for all who seek to be more in touch and in tune with their true self.

# To have your experience considered for inclusion in The Diary Healer, I invite you answer any or all of the following questions:

- 1. List your reasons for diary-writing/journaling.
- 2. How often do you write in your diary/journal?
- 3. What characteristics does your diary have? Do you put all your thoughts into one diary, or do you have different diaries for different parts of your life, e.g. a recovery or mood/food diary plus a daily diary about everyday things? What works best for you?
- 4. Do you include other forms of self-expression, such as poems, or thoughts other than your own? E.g. affirmations, letters, press cuttings? Examples?
- 5. How do these various diary components add/contribute to your sense of self and wellness? Can you describe why?
- 6. Comparing your early diary entries and later entries, for instance: i) before seeking professional help, ii) during treatment, iii) after recovery: what differences do you see? (E.g. in self-expression, connecting with self, thoughts, feelings, mood, treating the diary as a confidante, ratio of every day matters to matters of self, analysing, rationalising, self-determination, etc.). Give examples/excerpts to illustrate the differences.
- 7. How has diary-writing been helpful to you? For instance, in relation to maintaining sense of self, while in grip of illness, managing/monitoring your meals, exercise and mood (thoughts and feelings)? In learning about your health concerns? In coping with lapses? Do the pages of your diary reveal improvement in these areas? What self-help/coping strategies do you use? Provide excerpt examples.
- 8. Comment on the diary as a self-help tool in relation to:
  - a. Privacy (a safe place to off-load thoughts and feelings—is privacy a factor for you? If so, can you explain why?)

- b. Shame/stigma (list example of where you have felt and stigma and this has influenced your behaviour mood and examples where you have off-loaded and reasoned your way to feeling okay about things).
- c. Constant companion (any time you need support you can reach for your diary—is this helpful at trigger moments? Describe situation examples; share excerpt).
- 9. Regarding the various stages of an eating disorder, when has the diary been most useful for you? For instance: recognising and treating the early symptoms, when recovery efforts start, as a step-down tool, as a relapse prevention tool? What strategies have you employed?
- 10. What are your views on the effectiveness/potential of diary-writing as a tool in recovering from an eating disorder? Do you see the benefits of diary-keeping as a tool best used in conjunction with a therapist/clinician, or on their own as a form of self-care?
- 11. Do you share your diary, or information from your diary, with your clinician/therapist/recovery guide? What do you see as the advantages/benefits of sharing your diary in this way? What are the challenges/disadvantages?
- 12. How important is it for you to feel like part of the treatment team in your own recovery? Like, to have a say in the decision-making, and feel understood and respected as a person? Does the sharing a diary/your writing help in this way? Can you tell me about this?
- 13. Has the diary-writing been helpful at times of extra stress/pressure in your life, not only with your eating disorder, but also in relationships and every day family/work situations? If so, how has it helped you cope?

#### **Further questions**

 Diary-writing is an intensely private affair. First and foremost we must write to and for our own self. How can we feel secure and safe, sharing our innermost thoughts and feelings on-line?

- 2. What are your views on the traditional pen-and-paper diary compared with on-line diary formats, social media formats, Apps, etc.? What are the benefits, limitations? Do you see a role for pen and paper today? What impact do the formats have, and how do they differ, in relation to privacy, trust, secrecy and authentic self?
- 3. What factors need to be considered re proceeding from writing for self versus writing to share (with therapist, family member etc.)?
- 4. Living in a world where communication is big business, almost everyone carries an iPhone, why do many people continue to feel lonely/isolated/out of touch with self and others? In communicating 'out there', via the Internet, does this facilitate or hinder healing within? What's the answer?
- 5. Thank you very much for sharing your diary experience. I will keep you posted.

June Alexander

E-mail: june@junealexander.com

## The Diary Healer: Invitation to Share your Life Experience in New Book [Adapted for App Users]

The Diary Healer will explore the development of apps in eating disorder care. I am

gathering feedback from apps' users. Anonymity is assured (unless you request your real

name). Your responses are invited to the following questions:

- 1. What apps have you tried?
- 2. Which app have you found most useful? How long have you been using it and how often do you use it?
- 3. Why is this app your favourite? List features that are particularly helpful.
- 4. Had you sought treatment before downloading the app that you like? Have you sought help since downloading the app?
- 5. How has the app been helpful to you? For instance, in relation to managing your meals, exercise and mood (thoughts and feelings)? In learning about your health concerns?
- 6. Can you suggest ways the app could be improved? What other features would you like it to have?
- 7. Comment on the app as a self-help tool in relation to:
- Privacy (nobody else needs to know you are seeking help—is privacy a factor for you? If so, can you explain why?)
- Cost (is this type of care more affordable for you? Is cost a prohibitive factor in seeking real-time care?)
- Constant companion (any time you need support you can reach for your Smartphone—is this helpful at trigger moments? Describe examples)
- 11. Convenience (no matter where you live, or what your commitments are, you can access this type of care?)
- 12. Regarding the stages of an eating disorder, when do you think the app most useful? For instance: recognising and treating the early symptoms, when recovery efforts start, as a step-down tool, as a relapse prevention tool?

- 13. What are your views on the effectiveness/potential of apps as a resource in eating disorder care? Do you see them as a tool best used in conjunction with a therapist/clinician, or on their own as a form of self-care?
- 14. Do you share your app information with your clinician/therapist/recovery guide? What are the advantages/benefits of this sharing for you?
- 15. How important is it for you to feel like part of the treatment team in your own recovery? Like, you get to have a say in the decision-making, and feel understood and respected as a person? Does the app help in this way? Can you tell me about this?
- 16. Consent and Acknowledgement: Do you give permission for any material you submit, to be selected and published in the book? What name do you wish to be used as acknowledgement? Pseudonym? First name only? Full name? Include title, website link if desired.
- 17. Thank you very much for sharing your app experience. June Alexander

E-mail: june@junealexander.com

## The Diary Healer: Invitation to Share your Experience in New Book [Adapted for Eating Disorder Support Organisations]

The Diary Healer explores the development of on-line narrative support in eating

disorder care via websites, blogs, and social media. Your responses are invited to the

following questions:

- What on-line support does your organisation provide for caregivers and sufferers of eating disorders?
- 2. What aspects of this support are most popular? List features that are particularly helpful.
- 3. Who is seeking support? Caregivers, partners, parents, sufferers? And at what stage of the illness?
- 4. In what ways does the on-line community offer most help? For instance, in relation to managing meals, exercise and mood (thoughts and feelings)? In learning about health concerns?
- 5. How can on-line groups be improved? What features are ideal?
- 6. Comment on the on-line support groups as a self-help tool in relation to:
- Privacy (nobody else needs to know you are seeking help—is privacy a factor? If so, can you explain why?)
- Cost (is this type of care more affordable? Is cost a prohibitive factor in seeking real-time care/support?)
- 9. Constant companion (e.g. you can reach for your Smartphone or go on-line at any time—is this helpful at trigger moments? Describe examples.)
- 10. Convenience (no matter where you live, or what your commitments are, you can access this type of care and support?)
- 11. Regarding the stages of an eating disorder, when do you think the on-line group/support is most useful? For instance: recognising and treating the early symptoms, when recovery efforts start, as a step-down tool, as a relapse prevention tool?

- 12. What are your views on the effectiveness/potential of on-line support and engagement as a resource for caregivers and sufferers in eating disorder care? Do you see them as a tool best used in conjunction with a therapist/clinician, or on their own as a form of self-care?
- 13. How important is it for people to feel like part of the treatment team in their own or child/partner's recovery? Like, getting to have a say in the decisionmaking, and feeling understood and respected as a person? Does the on-line support help in this way? Can you tell me about this?
- 14. Consent and Acknowledgement: Do you give permission for any material you submit, to be selected and published in the book? What name do you wish to be used as acknowledgement? Pseudonym? First name only? Full name? Include title, website link if desired.
- 15. Thank you very much for sharing your experience.

June Alexander

E-mail: june@junealexander.com

## The Diary Healer: Invitation to Share your 'Evidence of Life Experience' in New Book [Adapted for health practitioners working in the eating disorders' field]

To have your experience considered for inclusion in The Diary Healer, I invite you

answer the following questions:

- Regarding the various stages of an eating disorder, when has the diary/journal/poetry writing been most useful for your patient? For instance: recognising and treating the early symptoms, when recovery efforts start, as a step-down tool, as a relapse prevention tool? What strategies have you employed?
- 2. What are your views on the effectiveness/potential of diary/journal/poetry writing as a tool in recovering from an eating disorder? Do you see the benefits of such creativity as a tool best used in conjunction with a therapist/clinician, or on their own as a form of self-care?
- 3. What do you see as the advantages/benefits of your patient sharing their diary/journal/poetry writing with you? What are the challenges/disadvantages?
- 4. How important is it for your patient to feel like part of the treatment team in his or her own recovery? Like, to have a say in the decision-making, and feel understood and respected as a person? Does the sharing of their writing with you help in this way? Describe the importance of trust.
- 5. Has the diary/journal/poetry writing been helpful at times of extra stress/pressure in your patient's life, not only with their eating disorder, but also in coping with relationships and every day family/work situations? If so, what skills or techniques do you encourage/employ?
- 6. Memoirs: Do eating disorder memoirs (published/on-line) have a role in ED recovery?

- 7. Do you find the reading of memoirs on eating disorders to be helpful, inspiring or triggering for your patients?
- 8. If a bank of memoirs and memoir excerpts were to be established to provide guidance and inspiration during early recognition, seeking treatment, recovery, prevention relapse, what types of excerpts would you suggest would be helpful? What criteria would you suggest as guidelines for selection?
- 9. Consent and Acknowledgement: Do you give permission for any material you submit, to be selected and published in the book? What name do you wish to be used as acknowledgement? Pseudonym? First name only? Full name? Include title, website link if desired.
- 10. Thank you very much for sharing your diary experience. I will keep you posted.

June Alexander

E-mail: june@junealexander.com

## Appendix F

## Samples of Questions put to Researchers and Health Practitioners Working in the Eating Disorder Field

The diary, as a genre, has strengths: shared personal accounts of mental illness can educate, provide hope to those experiencing similar symptoms, describe outcomes of various choices, and model coping strategies for others engaged in similar struggles. First person accounts also tend to be engaging and accessible to those with little or no formal understanding or training in mental health issues, as well as to mental health professionals. The diary also has weaknesses and limitations. Discuss.

- In the eating disorder research field, little research has been done on the value of the diary as self-help, therapeutic and educative tool.
   Discuss why more research is warranted and what focus such research should take.
- Remarkably few researchers have used solicited written diaries when studying mental health interventions (possibly because the use of written diaries challenges methodological tradition) even though diary approaches offer a feasible and valid way of studying the outcomes of mental health interventions. Discuss and draw on what evidence-based research there is, to show why more extensive research is overdue in addressing a) the healing power of diary-writing in patient care and b) the educative value in nurse and medical student training.
- Comment on the following, from the therapist/nursing point of view:

It is the responsibility of ill people to 'witness their own suffering and to express this experience so that the rest of us can learn from it. Of course others must be willing to learn; society's reciprocal responsibility is to see and hear what ill people express'.

#### Arthur W Frank, At the Will of the Body, p. 123

Writing helps others understand unconscious attitudes, beliefs and behaviour that may help to mitigate and improve understanding, and therefore improve treatment interventions. Writing can help overcome/cope with blame and shame, provider disinterest, annoyance, degradation and dehumanisation, poor prognosis/fostering dependence, and coercion and lack of 'real' choice.

Narratives can provide insight into the patient's perception of their therapeutic and rehabilitation needs and, in conveying patient experiences, can encourage healthcare professionals to reflect on their practice and respond to service-user needs. Discuss.

My treatment team did not really treat me as an individual but rather as any other ED patient they had ever had, not altering any of their methods based on circumstance. Their thoughts were to take everything I had (phone, iPod, laptop, clothes, friends etc.) and not to give them back until I was eating properly again. This might work for some people but I have always been a very stubborn person and the more they took, the more I refused to cooperate. I felt violated and not respected. I was treated as a naughty child rather than as a young adult who was going through a really tough time. I resented the way I was treated and I think it only added to the length of time I spent in hospital. I am fully weight-restored

now and seemingly 'recovered' however, I still have major issues with food and body image. Due to my unwillingness to cooperate with treatment I wasn't open with a lot of my thoughts and feelings and a lot of issues went unaddressed as my team seemed to think that as long as I was gaining weight and eating properly things were going well. [**Patient, major hospital, 2013**]

- 1. Part of the Treatment Team: Patients are more likely to improve when they feel listened to and understood, and respected, by their health practitioner and from the practitioner recognising change in readiness to recover as important progress, rather than seeing concrete behaviour change as the only goal. Equally important, the doctor/nurse needs to feel listened to and understood, and hopefully respected. How can writing be a collaborative member of the treatment team? Writing rather than talking about feelings and thoughts is often easier and more effective. How can diary-writing help change the discourse of mental illness as a limitation, and of social attitudes toward people with mental illness, and as a teacher for the health profession? Discuss.
  - The diary, as a genre, has strengths in meeting mental health challenges.
     The diary also has weaknesses and limitations. Discuss.
  - In the eating disorder research field, little research has been done on the value of the diary as self-help, therapeutic and educative tool. Discuss.
  - Narratives can provide insight into the patient's perception of their therapeutic and rehabilitation needs and, in conveying patient experiences, can encourage healthcare professionals to reflect on their

practice and respond to service-user needs. How can the diary allow the treatment team to be better informed to provide the patient with the support and understanding they need to recover?

- Eating disorder patients are more likely to improve when they feel understood, and respected, by their health practitioner and from the practitioner recognising change in readiness to recover as important progress, rather than seeing concrete behaviour change as the only goal. Equally, the doctor/nurse needs to feel listened to, understood, and hopefully respected. Can writing be a helpful, collaborative member of the treatment team? Challenges/advantages? Secrecy/trust? Bridgebuilder?
- Writing rather than talking about feelings and thoughts is often easier and more effective for people with an eating disorder, or for people who have experienced trauma, or other life challenge. Discuss.
- Pen and paper versus digital forms of diary-writing. Discuss pros and cons.

# Appendix G

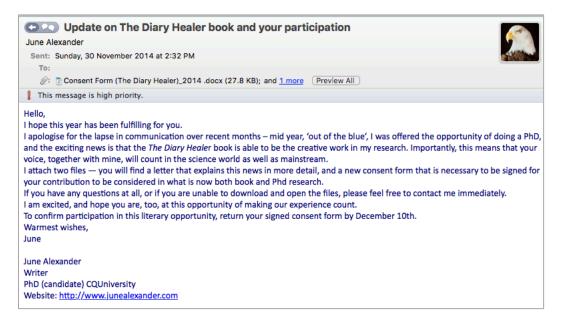
# Calendar of Meetings at Academy for Eating Disorders' International Conference, New York, March 2014

Wed 26	Thu 27	Fri 28	Sat 29
AED conf: NY			
Contact Debra S 650-704-5668	Hunna tonight		
7:30 AM		7 AM Bridget Whitlow-online sharing (USA) Hotel lobby	
Meeting_ Jenna Tregarthen (Standford Uni, USA) re Recovery Record app/smartphones	7:45 AM		
Cook renectively record apprinter chores.	Breakfast-Andrea LaMarre (Canada) - diarist contributor/researcher/reader Meet in Lobby	8 AM Steffi Bauer (Germany) smartphones	8 AM Gurze Catalogue editors Michael and Kat Cortese (USA) re publicity Breakfast at conference venue
		9 AM Michael Levine - Chief reader, mentor, contributor	
11 AM NEDA HQ - CEO Lynn Grefe re contribution (USA) re online storytelling and sharing		11-15 AM Alison Darcy (Stanford Uni) smartphone a	11:30 AM
			Michel, Vazzano (USA) diary as theraped
	12 PM		
	Lunch-Yael Latzer and Rachel Bachner (Israel) -Family influences	12:15 PM Ivan Elsler (UK) - family influence	12:15 PM Megan Jones-lunch Re Lantern App (Stanford Uni, USA) Hotel lobby
		-	
			1:30 PM
		1:45 PM LeGrange, Goldschmidt (USA)-family Lobby	Meeting: Maureen Donohue-Smith re therapeutic writing Lobby
		3:45 PM	
	4 PM	Jenny Thomas (USA) memoirs & The Diar	
	Karine Berthou - Survivor and Founder		
	Succeed Foundation (UK) [storytelling on videos] Lobby	4:30 PM Laura Collins Lyster-Mensh blogger/ advocate/carer/contributor-USA Lobby	
5:30 PM Monte Nido Treatment Center-Carolyn Costin (founder/director) diarist/survivor	5:30 PM The Diary Healer - self-help skills/family influence Janet Treasure, Ulrike Schmidt (UK)		

# Appendix H

### Samples of E-mail Correspondence to Diary Participants

# Samples of E-mail Communication with Diary Participants Throughout the Book Creation Process



Hello,

I hope this year has been fulfilling for you. I apologise for the lapse in communication over recent months—mid-year, 'out of the blue', I was offered the opportunity of doing a PhD, and the exciting news is that the *The Diary Healer* book is now the creative work in my research. Importantly, this means that your voice, together with mine, will count in the science world as well as mainstream. I attach two files—you will find a letter that explains this news in more detail, and a new consent form that is necessary to be signed for your contribution to be considered in what is now both book and PhD research.

If you have any questions at all, or if you are unable to download and open the files, please feel free to contact me immediately. I am excited, and hope you are, too, at

this opportunity of making our experience count. To confirm participation in this literary opportunity, return your signed consent form by 10 December 2014.

Warmest wishes,

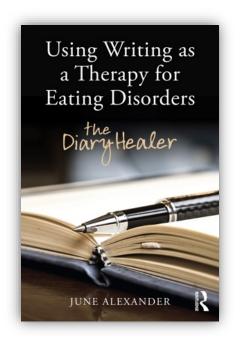
June

# E-mails to All Diarist Participants

### Important Update, November 25, 2014

November 25, 2014

The Diary Healer—Using Writing as a Therapy for Eating Disorders



I write with an update on the writing of the above book and to share an exciting new development. Early this year you responded to an on-line invitation to share the experience of diary-writing while developing and/or recovering from an eating disorder.

The invitation related to a book I am writing, called *The Diary Healer—Writing as a Therapy for Eating Disorders.* Routledge (London) is the publisher.

The invitation, to which you kindly responded, appeared on my blog: http://www.junealexander.com/2014/02/calling-diary-and-journal-writers-withexperience-of-an-eating-disorder/ Following your initial expression of interest, you completed a questionnaire and submitted this for consideration of inclusion in *The Diary Healer*. Your contribution is safely stored on my book database.

Now to the big news, which involves you.

In May this year, I was offered a place as a PhD student in Creative Writing at CQUAustralia. My supervisors encouraged this path, suggesting *The Diary Healer* could be the creative work for the PhD. In this way, the book would be more than a mainstream book; it would be an academic book; it would contribute to science. It would have a louder 'voice'. The second part of my thesis would comprise an exegesis, a paper in which the themes in *The Diary Healer* are explored in detail to reveal gaps in eating disorder research and suggest ways forward.

This amazing opportunity, of moving from patient to researcher, meant I needed to shift focus for a few months to embrace a steep learning curve in adapting to the world of academia. The effort has been amazingly worthwhile—I have learnt much to complement the patient voice in *The Diary Healer* and last week successfully met requirements for PhD confirmation of candidature.

Now I am free to focus on the writing of *The Diary Healer* and this is where you come in.

When we communicated early this year, you gave consent for your writing to be considered for inclusion in *The Diary Healer* book.

Now that this book is part of a PhD, and parts thereof may be published and referred to as a scientific document, your consent is required afresh, for consideration of inclusion in not only the book but also the PhD.

For your contribution to be considered for inclusion in *The Diary Healer*, and the PhD, complete the attached form and **e-mail to:** 

june@junealexander.com by December 10<sup>th</sup> 2014. Consent is essential for your contribution to be considered for inclusion.

I wish to thank you for courageously accompanying me on this deeply meaningful literary journey and for generously sharing your experience to educate and help others. Routledge plans to release *The Diary Healer* mid-2015. Hence the writing and completion of the manuscript is now my prime focus.

Please feel free at all times to write with any queries. For instance, if you wish to re-read your earlier submission, and haven't a copy, let me know and I will e-mail your submission to you. I will keep you informed throughout this book-writing process, and will provide opportunity for you to read/update/edit any parts of your contribution selected for inclusion in the manuscript, prior to submission to the publisher. You can expect to hear from me regularly over the next few months during this book-writing phase. I plan to submit the manuscript to Routledge by the end of March 2015.

Thank you once again. I look forward to your response re the Consent Form. Best wishes,

June Alexander

june@junealexander.com

### Consent Form, December 29, 2014

Hello,

I hope this letter finds you enjoying life, and I wish much happiness for you in 2015.

I wish to thank you for responding to my blog invitation early this year, on

sharing your diary (journal) experience for a new book, The Diary Healer.

Excitingly, this book, The Diary Healer, is now also the creative work in a PhD,

which I began halfway through this year. The focus of my research is to focus attention

on the need for more patient-centred healing, for instance by using narrative therapy,

such as diary-writing.

Importantly, this means that your voice, together with mine, will count in the science world as well as mainstream.

I attach two files—you will find a letter that explains this news in more detail, and a consent form that is necessary to be signed for your contribution to be considered in both book and PhD research.

If you have any questions at all, please feel free to contact me immediately.

I am excited, and hope you are, too, at this opportunity of making our experience count.

To confirm participation in this literary opportunity, return your signed consent form by January 10th.

Routledge is planning to release the book about mid-year, so I am busy writing!

I will keep in touch with you and you will have opportunity to read and edit any

excerpts that you have provided, before the manuscript is submitted to the publisher.

First however, for your kind support to be recognised and considered, I need your consent form.

I look forward to hearing from you.

Warmest wishes,

June

June Alexander

PhD (candidate) CQUniversity

Website: http://www.junealexander.com

### Acknowledgement List—Confirming Name, January 4, 2015

Construction Const

### [E-mail to more than 100 participants]

#### Hello, this is an open letter to all participants in The Diary Healer journey:

I would like to acknowledge your support and contribution to this important work—*Using Writing as a Therapy for Eating Disorders*—*The Diary Healer*, which is about to be submitted to the publisher, Routledge Mental Health (London).

To have your name included in the Acknowledgement Section of the book,

respond NO LATER than July 15, with the <u>exact wording</u> of how you wish your name to appear in print; for instance, your full name, or first name only. Therefore:

- 1. Would you like your name to be included on the Acknowledgement List?
- 2. What name do you want to appear in print (first name/first and second name)?

#### **Contributions selected for manuscript**

E-mails have been sent in the past two weeks with details of contributions selected for inclusion in the manuscript. Selecting the material has been a difficult process because every story deserves to be told in full, but even if you have not received a letter containing detail of parts of your contribution selected for the book, I wish to assure you that your contribution remains important and you remain an integral part of *The Diary Healer* PhD journey. I acknowledge your generous participation to this book and associated research, and invite your response to the above invitation for inclusion on the Acknowledgement List.

For your name to appear on the Acknowledgement List, respond by July 15th.

If you wish to notify of additions or edits in relation to your submissions for the

book this is the final opportunity, with the deadline for all edits set at July 15.

Feel free to write with any query. I look very forward to your response and continuing this exciting journey with you. Your experience and your voice counts.

Warmest wishes,

June Alexander

PhD (candidate) CQUniversity

Website: http://www.junealexander.com

Forthcoming Book Release Update, May 22, 2016

The Diary Healer - release soon
June Alexander
Sent: Sunday, 22 May 2016 at 11:47 AM
To:
 Sent: Using Writing as a Therapy for Eating Disorders\_FAW.tif (3.7 MB) Preview

Dear Participants in The Diary Healer,

I hope this finds you and your loved ones in a sunny, bright place on your life journeys. I

have good news to share:

- I have just returned to Melbourne from USA, where I received an international award for public awareness and advocacy at the Academy for Eating Disorders annual conference. I feel this award belongs to you and others, as well as me. Read about it on my blog post: http://www.junealexander.com/2016/05/join-the-cicadaschorusing-loudly-to-spread-advocacy-about-eating-disorders-aroundthe-world/
- Excitingly, the book Using Writing as a Therapy for Eating Disorders— The Diary Healer (https://www.routledge.com/Using-Writing-as-a-Therapy-for-Eating-Disorders-The-diaryhealer/Alexander/p/book/9781138788374) is in production stage with the publisher, Routledge (London), which means it is near to the stage when it will be sitting on book shelves! First Proofs have been completed. Second Proofs will be next, in the next few weeks, and if the editor has any last-minute inquiries relating to any content that you have kindly submitted, I will contact you. So keep an eye on your Inbox:-)
- The publisher expects to release the book in July—yes, July this year.
   Soon!

 Writing this book has been, and continues to be, an amazing, uplifting journey. Thank you sharing this journey with me, and for your patience; feel free to write any time.

With gratitude and warmest wishes,

June

June Alexander

PhD candidate, Central Queensland University

Website: http://www.junealexander.com

### E-mail to Some Diary Participants

### Consent Form Reminder, January 4, 2015

Gentle reminder\_Participating in The Diary Healer book - consent form to be signed
June Alexander
Sent: Sunday, 4 January 2015 at 5:16 PM
To:
 Consent Form for The Diary Healer\_2014-2015.docx (26.6 KB);
 The Diary Healer\_participation update\_November 2014.docx (4 MB)
Preview All
This message is high priority.

Hello,

I hope this letter finds you enjoying life, and I wish much happiness for you in 2015.

Firstly, I wish to thank you for responding to my blog invitation in 2014, on

sharing your diary (journal) experience for a new book, The Diary Healer.

Excitingly, this book, The Diary Healer, is now also the creative work in a PhD. My

research aims to draw attention to the need for more patient-centred healing, for

instance narrative therapy, such as diary-writing.

Importantly, this means that your voice, together with mine, will count in the

science world as well as mainstream.

I attach two files—a letter with more detail, and a consent form that is necessary

to be signed for your contribution to be considered in both book and PhD research.

Importantly, because I am writing the book chapters now, your consent is required for your diary response to be included in *The Diary Healer*.

To confirm participation in this literary opportunity, please return your signed consent form as soon as possible.

You will have opportunity to read and edit any excerpts that you have provided, before the manuscript is submitted to the publisher.

First however, for your kind support to be recognised and considered, I need your consent form. If you have any questions at all, please feel free to contact me immediately.

I look forward to hearing from you.

Routledge is planning to release the book about mid-year!

Warmest wishes,

June

PS: I apologise for writing at a busy time of year but want to remind you of this opportunity to make your experience count for others.

June Alexander

PhD (candidate) CQUniversity

Website: http://www.junealexander.com

Consent Form Urgent Reminder, March 1, 2015

Urgent\_The Diary Healer book - consent form to be signed

 June Alexander

 Sent:
 Sunday, 1 March 2015 at 5:37 PM

 To:
 ?

 ?:
 Consent Form for The Diary Healer\_2014-2015 .docx (26.6 KB)

 Preview

 Itis message is high priority.

Hello,

I hope this finds the sun shining in your day and in your life.

I wish to thank you for responding to my blog invitation in 2014, on sharing your journaling (and other forms of narrative, including poetry) experience for inclusion in my new book, *The Diary Healer*. The manuscript is taking shape and nearing completion!

Excitingly, this book, *The Diary Healer*, now also the creative work in my PhD, draws attention to the need for more patient-centred healing, for instance narrative therapy such as diary-writing. So that your work can be considered, and your experience count in not only this book but also the research field, I need you to sign the attached consent form, and return to me as soon as possible.

You will have opportunity to read and edit excerpts, before the manuscript is submitted to the publisher.

If you have any questions at all, please feel free to ask.

I look forward to hearing from you :-)

Routledge is planning to release the book this year! (See link below). Warmest wishes,

June

June Alexander

PhD (candidate) CQUniversity

Website: http://www.junealexander.com

# Appendix I

# **Example of Developing and Maintaining Trust, and Honouring Ethical Responsibilities, with Research Participant**

Five months after initial intake of diary respondents, a research respondent revealed panic and doubt in sharing her story. 'B' was the only one, out of 70 participating diarists, who expressed a sudden surge of fear in 'going public' and releasing her story to the world. She was one of several research participants who became involved at the encouragement of their therapist, who believed the process of participation would be helpful and healing for their patient. In May 2014, 'B' wrote:

I am a patient of Dr F and he strongly suggested I get in touch with you regarding the writing/poetry/journaling I have done during my ED recovery process. I would be happy to share with you if you are interested.

I invited 'B' to be a diarist participant. She responded quickly, despite feeling overwhelmed, and my intuition and expertise as both writer and person with experience of an eating disorder indicated strongly that the contribution from 'B' would be a gem, which until now had been kept private. It was my challenge to help 'B' feel sufficiently safe and secure to release this gem of illness insights to the world. She wrote:

I understand what you are asking for regarding my journaling/poetry, but honestly I wouldn't even know where to begin. I have over five volumes of journals and hundreds of poems. All in all its thousands of pages. There is no beginning and no ending. Some I've shared, and some I have not. I'm still on this journey and I can't say that I'm "recovered", so I'm not sure if what I have to offer is what you are looking ... I am happy though to share some of my writing and poetry with you, so I'm sending some words from the past and some are more recent.

Her next message illustrated the disconnection between mind and body that is experienced when living with anorexia nervosa:

"Feeling like I did not belong." Those words you wrote, when I look back, I realise I've felt that way my entire life. I've been following a guide not designed for me. I wrote this excerpt with those feelings in mind ...

When I was born, someone fitted me with a rulebook ... a "guide to being", so thick and stifling that the weight of its pages has kept me paralysed in an invisible fog my entire life. ... And even then I wonder. Would that be enough to burn the book and rip this virulent, emaciating bond? Because you see there's fate. And is there really anything more powerful than fate? And what if she has already won?"

I wrote that in 2012 ... I wish I had done a better job at dating my journal entries.

Within days, 'B' sent another message, exhibiting illness traits of self-doubt and unworthiness:

I'm sorry I haven't sent you any of my journal entries. I have spent the last week reading through them and re-living all that I've been through these last few years and I'm afraid it's causing a lot of pain and triggering me in an unhealthy way. Maybe I'm not ready ... A story I have not yet found peace with ... I know my poems are not "real" poems. I've never studied poetry or learned the proper way to write, but I hope some of what I've sent can be useful for your book. I think I'm afraid to reveal too much. And my

journal entries are SO revealing that it makes me feel like I'm baring my naked soul if I send them to you. Poetry can be quite concealing, but journal entries are so bare.

.... I'm grateful for the connection I feel with you now ... I'm willing to share my story ... I'm just not sure how.

E-mail communication continued and in December 2014, 'B' returned her signed permission form. She chose to have her real name used, providing she had opportunity to edit text she did not feel comfortable sharing once I had decided what to print. In July 2015, a year after her initial contact, 'B' was invited to review the context and the content of her contribution selected for inclusion in *The Diary Healer*. She responded:

I am sending you the edits I made for what you are including in your book ... This [process] is somewhat difficult for me because I have only shared my writing with a very few.

My response to 'B', while empathic, understanding and reassuring, was mindful of being clear about ethical and publication limitations and boundaries. My main concerns were to uphold ethical considerations to respect and protect 'B'. While aware her psychiatrist, who had encouraged her to share her story, was providing her with ongoing support and care, her correspondence indicated a high vulnerability to illness triggers. A suggestion that only part of a poem could be published due to space restrictions, for instance, could be misinterpreted as personal unworthiness or criticism. At the same time, I recognised that the graphic and candid descriptions from 'B', including diary excerpts and reflections in both prose and poetry, provided an exceptional presentation and record of illness experience. My latest message to her

included a Word Document file, with her edits inserted in the manuscript, for a final check. As the manuscript limit of 90 000 words was already exceeded, extra words could not be considered, only if others were deleted. I suggested to 'B' that she track any editorial amendments to attached Word Document file and return it. I encouraged her to check her poem extracts were in correct stanza form, and separated where applicable, and that direct quotes and reflections of today were distinguished from diary extracts, in keeping with the book's theme.

Despite my care to avoid 'speaking to' her illness, anxiety was triggered within 'B'. She felt 'rushed' and sought more time, stating if her words were to be published in a book she could not release them until she felt they were written as she would write them. I offered to postpone her deadline, and send the entire poetry chapter, to help her see where her story was in context to the book as a whole, and other chapters that featured her contributions.

'B' responded that she would like to read the entire set of chapters in which her material was embedded and, with the extended deadline, she hoped she could contribute to the book. Without the opportunity for face-to-face meetings or phone calls, this was a delicate part of the practice-led process. I had to rely on written communication to help 'B' feel safe and secure, and to trust me sufficiently to share her story publicly for the first time. I was devoting a lot of time to providing reassurance and building a rapport and trust with 'B', aware at any time she could withdraw her involvement as a research participant. The illness, I knew, thrived on isolating the sufferer, especially from people or activities that might be seen as supportive to healing

and re-connection of authentic self. We lived on different continents, and our only form of communication was on-line. This was not an ideal situation for establishing a trustbased rapport. However, my experience in living with the illness enabled me to empathise with 'B', while at the same time, refusing to 'feed' or strengthen her illness traits.

'B' expressed concern about her diary excerpts being paraphrased and mingled with others; she sought and received time to reflect, because in summoning the courage to break free of the secret life of the eating disorder, and share the raw record of her suffering, the thought of altering or deleting even one word was for her perfectionist nature quite terrifying. Together we found a solution. 'B' offered more excerpts, comprising shorter poems and diary excerpts. Original quotes from 'B' and other diary participants replaced those chosen earlier from published diarists, including Nin, because they related more directly to both the diary's chronicling of disconnection and re-connection with self during the process of developing and recovering from an eating disorder.

I wrote:

Dear 'B',

... I will carefully consider appropriate and respectful placement for your diary excerpts, maintaining each one's entirety, in the manuscript. Most likely, the more brief excerpts, both prose and verse, will be chosen, because these lend themselves to being a stand-alone, powerful 'voice' at the start and end of chapters, for instance. When I

complete the process of selecting and inserting your excerpts, I will send you the entire manuscript so that you can see where your voice is heard.

'B' responded the next day:

I cried all the way through this response you sent me. I could actually feel you sitting right beside me, hugging me and sharing your strength, wisdom and courage. It's beyond words how healing it is to feel understood and accepted. So I Thank You from the bottom of my heart ... Your suggestion is wonderful and I look forward to reading the manuscript. Thank you for your careful consideration and understanding.

The following month, August, illness again triggered self-doubt in 'B' but she persevered, checking her content in the manuscript, returning it on time and adding evidence of insight: 'I feel I'm being too picky and difficult and I understand if it's easier to just leave all this out.'

The following week she confided:

It's comforting to feel your understanding. This entire process has caused me to re-examine so much of what I've journaled and begin to feel safe in sharing at least a tiny bit of my story. It astonishes me how many words I've written and I feel like there is no way I could ever put order to it all, even though I have an overwhelming desire to share in a way others could understand. If I could help just one person it would be worth it. ... I feel privileged to be a part of this book because the 'mission statement' you describe is the reason I came out of treatment with my body 'healed,' yet my mind severely damaged. ... I know for sure though that I'm trying desperately to recover not

only from my illness, but also the trauma of treatment and the guilt I feel for the disconnection [that happened] ...

In February 2016, when the manuscript was in the production phase of publishing, 'B' wrote in response to a general research participant update:

Your message reached me deeply; reminding me that I'm not alone ... I've never met another ED patient/survivor I could really relate with, yet with you there's something special.

# Appendix J

### **Specimen Permission Letter for Text**

Dear Permissions Manager,

I am preparing an academic book entitled [book title] which will be published by [imprint] in [year]. It will be published in [hardback/paperback] and is expected to cost [price]. The print run will be [number] copies. The material will also be produced in e-Book format as a verbatim digital copy of the printed work (i.e. it will be used in exactly the same context as the printed version, and without alteration). In e-Book format the cost will be [the same price as the hardback (if hardback only); the same price as the paperback (if dual edition)].

I would like your permission to include the following material from one of your publications.

Title

Year of publication

Author/editor

Page number(s) and total number of words and/or Figure/Table number

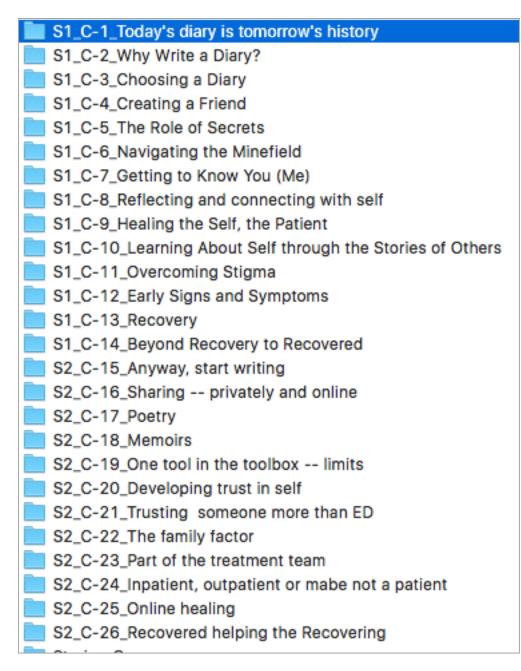
I understand that you control the rights to this material. I would be very grateful if you could grant permission for its use as soon as possible, stating any credit lines or fees that you require. If you do not control these rights, please let me know to whom I should apply. We are seeking non-exclusive world English language rights and will reproduce the material as part of the complete text in print and electronic formats for distribution throughout the world.

Yours faithfully,

# Appendix K

# The Diary Healer—Refinement of Chapters

## December 2014



### July 2015

SECTION 1: WRITING FOR SELF

- S1\_C-1\_ Why Write a Diary?
- S1\_C-2\_ Choosing a Diary
- S1\_C-3\_ Creating a Friend
- S1\_C-4\_ The Role of Secrets How the Diary Can Dupe You
- S1\_C-5\_ Navigating the Minefield of Abuse
- S1\_C-6\_ Getting to Know You (Me)
- S1\_C-7\_ Reflecting and Connecting with Self
- S1\_C-8\_ Healing the Self, the Patient
- S1\_C-9\_ Learning About Self through the Stories of Others
- S1\_C-10\_ The Many Marks of Stigma
- S1\_C-11\_ Early Signs and Symptoms
- S1\_C-12\_ Recovery
- S1\_C-13\_ How the Diary Helps Us to Move On
- SECTION 2: WRITING FOR THERAPY
- S2\_C-14\_ The Connector in the Toolkit
- S2\_C-15\_ Memoirs When Influence Depends On Timing
- S2\_C-16\_ Look For Me In Poetry
- S2\_C-17\_ Developing Trust In Your Self
- S2\_C-18\_ The Family and Healing
- S2\_C-19\_ An Icebreaker For Every Occasion
- S2\_C-20\_ Hitting the Send Button
- S2\_C-21\_ Setting Free The Therapist Within
- S2\_C-22\_ Supporting The Home Base Through Story-Sharing
- S2\_C-23\_ The Diary's Role in Behavioural Health Technology
- S2\_C-24\_ Staying Truthful to You
- S2\_C-25\_ Where to Get Help and Support
- Afterword: Cynthia Bulik

### January 2016—the Chapters sent to Production

TDH\_S1-C1\_Why Write a Diary\_2015-4(1) TDH\_S1-C2\_Choosing a Diary-2015-5 TDH\_S1-C3\_Creating a Friend\_2015-6 TDH\_S1-C4\_The Role of Secrets-How the Diary can dupe you-2015-7 TDH\_S1-C5\_Navigating the Minefield of Abuse\_2015-8 TDH\_S1-C6\_Getting to Know You (Me)\_2015-9 TDH\_S1-C7\_Reflecting and Connecting with Self\_2015-10 TDH\_S1-C8\_Healing the Self\_The Patient 2015-11 TDH\_S1-C9\_Learning about Self through the stories of others\_2015-12 TDH\_S1-C10\_The Many Marks of Stigma\_2015-13 TDH\_S1-C11\_Early Signs and Symptoms- 2015-14 TDH\_S1-C12\_Recovery\_2015-15 TDH\_S1-C13\_How the Diary Helps us to Move on\_2015-16 TDH\_S2-C14\_The Connector\_2015-18 TDH\_S2-C15\_Look for Me in Poetry\_2015-19 TDH\_S2-C16\_Developing Trust for Today and Tomorrow\_2015-20 TDH\_S2-C17-The Family and Healing\_2015-21 TDH\_S2-C18\_A Translator and Informant\_2015-22 TDH\_S2-C19\_The Internet as a Diary Medium\_2015-23 TDH\_S2-C20\_Newer Forms of Face-to-Face Support\_2015-24 TDH\_S2-C21\_Sharing Stories in Online Communities\_2015-25 TDH\_S2-C22\_The Diary's Role in B...ioural Health Technology\_2015-26 TDH\_S2-C23\_How Will the Story in Your Diary Play Out?2015-27 TDH\_S2-C24\_Using Your Diary to...eate a Narrative for Others\_2015-28 TDH\_S2-C25\_A Participant and Observer of Your Own Life\_2015-29

# Appendix L

## Summary of Chapters in the Diary Healer

### Section 1: Writing for Self

### S1-C2: Why Write a Diary

All you need to start a diary is a pen and paper, or a computer, or a keyboard on an electronic tablet or phone. But then what? Diary-writing can help you to connect with your thoughts and feelings. Skills can be learnt to help with problem-solving, time management, relaxing, trusting intuition, building self-belief and improving selfexpression.

### S1-C2: Choosing a Diary

Choosing a diary is like forging a friendship. It will be your recorder, guide and storyteller. You might like to mesh everything into one diary or choose several diaries to focus on aspects such as:

- Recording everyday events
- Emotional healing and development
- Describing dreams or dreaming, aims and ambitions
- Logging eating disorder recovery (or other health goals)
- You might have an on-line diary and a paper diary. Having a safe place to turn to is what matters most.

### S1-C3: Creating a Friend

The essence of a diary is about being a friend with your self. The diary is like a trusted,

best friend, who knows all about you and loves you anyway. Sometimes, people seem

friendly at first but later are found to have ulterior motives. Shame can be felt in

admitting I've made a mistake. When you have an ED, avoidance may kick in and lead to layers of deceit, not only with friends and family but also with your diary.

### *S1-C4: The Role of Secrets—How the Diary Can Dupe You*

Secrets affect ability to be true and honest to self and to others. Dealing with secrets of which you are aware, or suspect, exist can be painful enough. But secrets of which you are not consciously aware, such as an ED, can be more sinister. Healing requires honest disclosure or at least acknowledgement of secrets related to ED and here the diary can provide a therapeutic bridge. Even before trusting your own identification and expression of thoughts and emotions to others, the patient may start fostering trust and releasing long-held secrets through diary dialogue such as blogs.

### S1-C5: Navigating the Minefield of Abuse

Research on whether sexual abuse and other forms of abuse are linked in any way to the development of eating disorders so far reveal no known or established risk factors that are specific to eating disorders—none. What is known is that when sexual abuse is present it makes the illness a lot worse, more complex and harder to treat. However the minefield can be cleared; peace can reign.

### S1-C6: Getting to Know You (Me)

Today, I LOVE FOOD. For 40 years, however, every meal was an ordeal, sandwiched between layers of anxiety and guilt. Without direction, the more I attempted to sort mental chaos in my diary, the more irrational I became in relation to real or perceived distressing events. However, gradually, the learning of diary-writing techniques was helping the diary evolve from a survival tool to a method for building self.

### S1\_C7: Reflecting and Connecting with Self

Without enough 'me' time for your self to sync with your body, threads may sever and, suddenly, connection may be lost. Your diary can store these lost or suppressed pieces and preserve them until you feel ready to reflect on and revisit them. Your diary can facilitate and nurture this process, helping you to eventually put suffering into a context that allows you to live fully in the present.

### S1-C8: Healing the Self, the Patient

Knowledge is power in healing from an eating disorder. But when you do not understand that you are sick, the illness may thrive, isolating instead of connecting you with helpful others. Writing in your diary can help you find a way when others might think you are self-centred or 'lost'. Even when not understanding my illness, doctors said: *'Keep writing'*. They believed in me when I could not, and I am eternally grateful.

### S1-C9: Learning About Self through the Stories of Others

Writing about your ED experience and sharing it in a safe and supportive environment, can help overcome the isolation and reduce the fear that characterises the illness. This process alone can help to define and distance you, as a person, from the illness. However there are many considerations.

### S1-C10: The Many Marks of Stigma

In this chapter, diary-writers discuss how writing has helped them to come to terms with, and rise above, their experiences of shame and stigma. Being stigmatised is like being marked with disgrace and second-class status. The process of writing and rewriting your story can relieve intense feelings of stigma and shame.

### S1-11: Early Signs and Symptoms

This chapter explores the thoughts and feelings, behaviours, and symptoms that accompany an ED. Writing copious rules and contracts, on what to eat and how to behave, may provide brief relief, but ED rules are doomed to fail. Therefore, during the ED, while the diary can serve as a trusted confidant at a time of extreme isolation, a haven in which to attempt to make sense of a tortuous world, it also can become embroiled with—and become a servant of—the eating disorder; a secret within a secret.

### S1-12: Recovery

Recovery of self and health from an ED requires painstakingly deciding which thoughts and feelings are genuine, and how they connect, to accomplish re-integration. Recovery involves re-connecting with your body—biologically, psychologically, socially, and spiritually. Your diary can assist by providing a place to sort thoughts, deflect triggers, resolve issues, and hone reflective and observational skills.

### S1-13: How the Diary Helps Us to Move On

Even when aware that clinging to a daily regime of weights, calories and exercise routines is playing your ED's game, severing these behaviours can be scary. There is more healing to do, but when self-re-integration passes halfway, decisions in favour of self and health, and healthy self and body, become easier. Your diary can help you accept this is part of your life story, and to focus simultaneously on 'now', rather than the losses.

### Section 2: Writing for Therapy

### S2-14: The Connector

When a therapeutic relationship is built on trust and respect, a diary can work as a patient-centred connecting tool to assist healing from an ED. Expectations of others, which you are not ready to embrace, can cause you to retreat more into ED and behave in ways that are truly not 'you'. However, with gentle guidance, and establishment of a trusting therapeutic relationship, the diary can help bring your authentic voice to the fore.

### S2-15: Look For Me In Poetry

A revelation in sourcing diary excerpts for The Diary Healer has been the popularity of poetry as a form of narrative expression in the ED recovery process. This chapter illustrates how poetry can assist healing in the lives of people with eating disorders, and their caregivers. By encouraging, allowing and prompting a new line of thought, poetry adds an important dimension to diary-writing as a healing tool.

### S2-16: Developing Trust for Today and Tomorrow

As a reflective and exploratory tool, the diary can help you discover or re-discover parts of yourself. This chapter shares examples of how the diary can help to establish selftrust through and beyond recovery. Besides a place to store and 'let go' of emotion, the diary can serve as your personal trainer.

### S2-17: The Family and Healing

Families do not cause an ED. However, the family's role in treatment and recovery is crucial. Keeping a written narrative can help caregivers take care of both patient and self.

The diary can be useful now and later, putting the illness in context of your life story. Stories by former patients, and memoirs by other caregivers also can be useful. However, deep contemplation is required regarding what the stories are about, and when to share them.

## S2-18: A Translator and Informant

Identifying and letting go of ED behaviours is only part of the healing journey, for a void may remain that is scary and hard to fill. Writing about both good and bad days puts your diary in the best position to assist self-renewal because the diary's many uses include that of being a two-way translator and informant. By sharing your diary with a trusted therapist they can help you accurately interpret, identify and challenge unhealthy beliefs and goals, and develop healthy beliefs, and self-care skills.

#### S2-19: The Internet as a Diary Medium

The diary is typically considered an intensely private document. However, in today's Internet-based societies, there may be a place for private and public diaries, with the bridge being an e-mail, blog, app or other social media tool. On-line resources add a new dimension to diary-writing. This chapter explores factors to consider when you feel ready to share your story with others.

#### S2-20: Newer Forms of Face-to-Face and On-line Support

A major part of recovery from an ED is about making relationships work. This includes the relationship you have with others and especially your body and your self. This chapter explores face-to-face and on-line support, and how the diary might assist the recovery process. For example, the diary can be a helpful tool when navigating the move from inpatient to community-based care.

#### S2-21: Sharing Stories in On-line Communities

Sharing the story of your ED on-line may be helpful for you and the reader but, as with every step on this healing journey, be wary of hazards. Preparation, with safeguards of filtering systems, will help to minimise risk of a negative impact.

## S2-22: The Diary's Role in Behavioural Health Technology

The diary's basic elements traditionally provide a tool for record keeping, nurturing, healing, reflection, creativity and spiritual discipline. Since the 1990s many Internet mediated technologies that allow on-line journaling and user interaction, have drawn on the traditional diary format. The Recovery Record app and Lantern app add diary-based options to the self-renewal kit, and are explored.

## S2-23: How Will the Story in Your Diary Play Out?

Some diarists write with an audience in mind. Sometimes the audience is the diarist's own 'self' with a specific name, like Kitty, in Anne Frank. The Internet takes 'sharing' to a new level, enabling diarists to share daily life with an immediate, often unknown, audience. Internet tools allow others to read, and contribute to, metaphorical diaries left open. The smartphone encourages use of diary tools that provide brief but swift, constant interaction. However, in reaching out there is a risk of overlooking the necessity of also looking 'in'.

## S2-24: Using Your Diary to Create a Narrative for Others

Writing a private diary is for you only, but in a memoir, the unknown reader deserves consideration. There is lack of consensus on how much detail should be shared with readers in memoirs on eating disorders. The diary is perhaps unsurpassed in its ability to help tell your truth. However, moving from a private relationship with your diary, to sharing with others requires much thought.

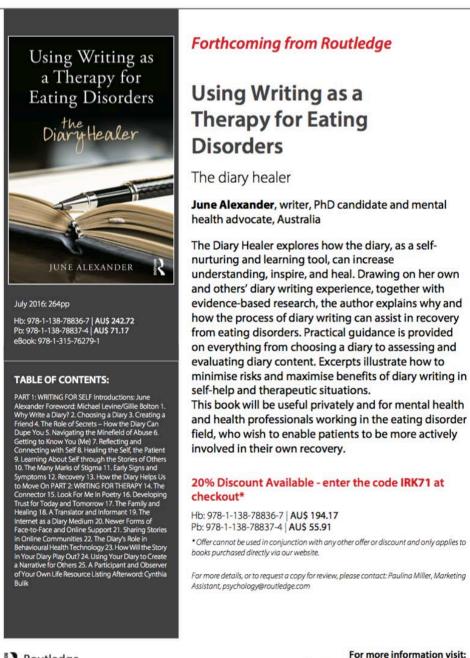
## S2-25: A Participant and Observer of Your Own Life

Sometimes, the process of writing is enough. Other times responses bound back from a shared and trusted safety net and I reflect on the essence of these written conversations in my diary.

# Appendix M

#### Announcement Samples

### Routledge Flyer Promoting Forthcoming Release of The Diary Healer



Routledge Taylor & Francis Group For more information visit: www.routledge.com/9781138788374

# Blog Announcing the Release of The Diary Healer

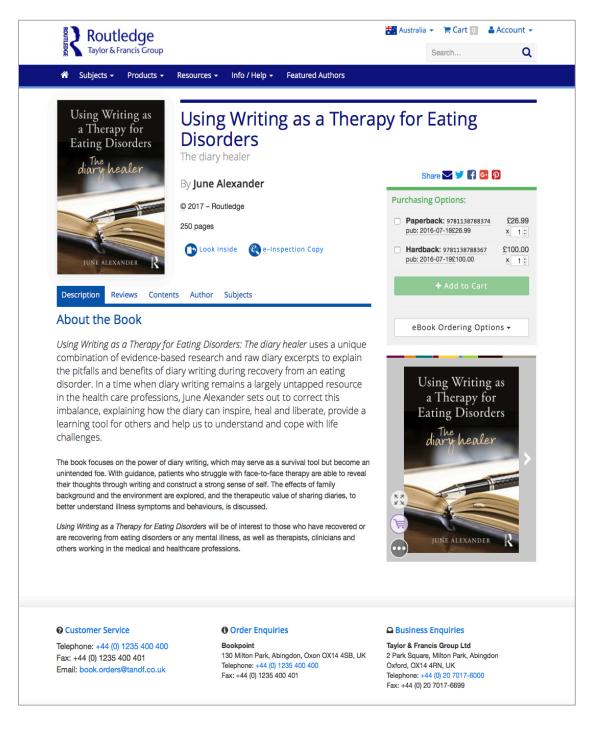
http://www.junealexander.com/2016/07/announcing-the-birth-of-the-diary-healer/

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## Book Release on Routledge Website

https://www.routledge.com/Using-Writing-as-a-Therapy-for-Eating-Disorders-The-

diary-healer/Alexander/p/book/9781138788374



# Routledge Mental Health 'Author of Month'

https://www.routledge.com/posts/10410



# Samples of Post Publication of The Diary Healer–Website and Podcasts

The release of The Diary Healer led to the launch of the website

https://www.thediaryhealer.com in January 2017.



Ruth Nelson, a Sydney psychologist interested in the use of the narrative for a healing and discovery process at the societal level, recorded a podcast in February 2017, in which I discuss the diary as a tool of expression for self and others. The download link is here:

http://traffic.libsyn.com/creatingspaceproject/Diary\_and\_Illness.mp3

An ED Matters podcast interview, recorded in San Francisco, May 2016,

describes the diary's role in my journey of self-discovery, and of others, culminating in

The Diary Healer:

https://itunes.apple.com/au/podcast/11-june-alexander-a-conversation-withjune/id1173632000?i=1000378587336&mt=2

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