

■ The Dementia Diaries

Matthew Snyman, Jessica Kingsley Publishers, 9781785920325, £9.99.

The Dementia Diaries provides accounts of what it is like to have a grandparent with dementia, as written from the perspectives of Brie, Fred, Sarah and Sam. Each takes turns to detail their experiences at different stages of the dementia journey. It is beautifully illustrated in the style of the “Wimpy Kid” diary series, so designed to appeal to a young demographic.

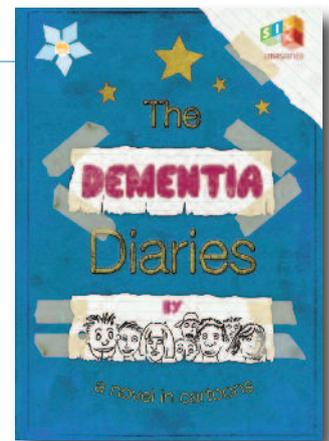
The first chapter introduces readers to each of the authors and their grandparent, giving an idea of who they are. These threads, for example their likes and characteristics, are featured throughout. The second chapter describes how the children became aware of their grandparents’ condition and the incidents that brought it to the fore. It details the

changes to family life, such as caring and living arrangements.

In the third chapter, the diary entries focus on coping with dementia and managing the condition on a daily basis, while the fourth chapter covers behaviour change in the grandparents. In chapter five, the excerpts give a range of tips on how to act with a grandparent with dementia. Chapter six focuses on the future, for example, the transition to care homes and, in Sarah’s excerpt, the death of her grandpa. The difficult issue of death is somewhat glossed over, which is understandable given that there is a lot of ground to cover and there are likely to be other resources directed at children on bereavement.

The book is written in an upbeat tone, and manages to maintain a balance between the sombre, delicate issues families will encounter and the lighter moments. Among the former are the inevitable anxieties when someone with dementia goes missing and when grandparents enter care homes. It is written with good humour where appropriate (and possible) and there is much warmth in the depiction of people with dementia.

There are activities designed to ensure the volume is interactive throughout, and these make use of technology such as YouTube, Facebook and Spotify. The authors have made efforts to ensure that references to popular culture are current. The book signposts to online support and links to



learning resources so that it may be used in schools.

Overall, this book will likely be an asset for families where there is a grandparent with dementia, and professionals working with these families. It would be wonderful to read a similar volume specifically for children living with a parent with dementia.

Melanie Hall is research associate, School of Education, University of Sheffield

■ Risk and Resilience: Global learning across the age span

Charlotte Clarke, Matthias Schwannauer, Julie Taylor and Sarah Rhynas (editors), Dunedin Academic Press, ISBN 9781780460635, £19.95.

Intended more for an academic than a practical audience, this book provides a useful resource for students of safeguarding and protective practice in health and social care by provoking debate and sharing the latest international research.

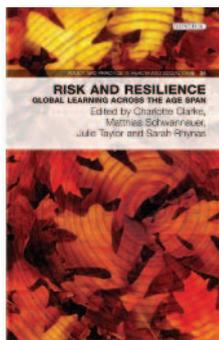
The chapters cover a wide range of topics that often provide a much-needed critical insight into concepts such as vulnerability, self-determination, autonomy and citizenship; concepts that are often used unquestioningly in both theory and practice. In particular, the focus on structural contributors to risk and resilience shows that this is a text that understands the

complexities of the field.

For those interested in support for older people, and particularly those living with dementia, this book is rare in the understanding and breadth it gives to consideration of risk, safety and resilience in this group. Five varied chapters are offered rather than the more usual token one.

I would especially note the good insight into new and potentially empowering approaches that may increase the resilience of people living with dementia such as self-management, relationship-building and robotics.

Isabelle Latham, senior lecturer, Association for Dementia Studies, University of Worcester



Resources

New guidance on pain management in people’s own homes has been published by the charity Dying Matters. The guide – called **Pain management for people who want to die at home** – gives information about the different options available. It includes information specific to people with dementia who find it difficult to communicate pain symptoms, referring to the Pain Assessment in Advance Dementia Scale and the National Council for Palliative Care’s guide *How would I know? What can I do?* The guidance, published during Dying Matters Awareness Week in May, can be found at www.dyingmatters.org

Care homes provider Four Seasons has teamed up with activity products specialist Active Minds to develop a **new range of products**, in addition to which a full suite of the existing activity products will be introduced in more than 300 of the company’s care homes. The idea is to monitor how this improves the day-to-day

experience of people with dementia. The products, designed for people with dementia, will be brought into Four Seasons’ Dementia Care Framework homes and will include arts activities, puzzles and games, reminiscence activities, sensory products and exercise activities. But the products, which are designed to be enjoyable while helping to keep people interested, engaged and active, will also be available more widely. Active Minds’ products can be found at www.active-minds.org

A new internet portal provides a single repository of information designed around the needs, preferences and goals of people with dementia and their carers. The **Liferaft** portal, available for £10 a month from Kuradocs, is said by the company to bring together up to date health and social care information which is easily accessible and allows recording of essential data. If the person with dementia has a favourite colour or tune, or prefers a hot drink to be served in a particular way, for example, ➤

➤ this can be recorded on the portal and shared with those involved in care. It can be accessed via computer, tablet and phone app. The portal has sections for recording medical data, goals, activities, personal history, likes and dislikes, and care needs, among other things. More details at www.myliferaft.com

A chair-based resistance exercise programme has resulted in significant benefits for frail older people, a new evaluation by the charity Royal Voluntary Service (RVS)

suggests. The exercise programme called **Move It or Lose It** was piloted with 60 older people in Banbury, Leicester, Oxford and Suffolk, and was found to produce functional improvement in 61% of participants within approximately three months. The programme, which has been taken up in a ward programme at University Hospitals of Morecambe Bay NHS Trust, also had a significant positive impact on mental wellbeing. The charity now hopes to extend the programme to other hospitals and primary

care providers. The RVS says that the programme helps to reduce loss of muscle mass and strength, which can be an underlying cause of falls and which often occurs following a period of illness, surgery or an accident. Find out more at www.moveitorloseit.co.uk

A life story app called **Just in Case** has been launched to capture people's life stories before they are no longer able to recall them because of dementia or memory loss. The app has six sections: personal details, important facts, habits,

likes, dislikes, and bucket list. "The information recorded in those sections will help other people learn about you as an individual and understand your needs, values and beliefs," says clinical psychologist Magdalena Galant-Miecznikowska, who developed the app. The app is intended to appeal to people who want to plan for their future and have the prospect, should the need arise, of being able to engage in appropriate and enriching activities based on life-long hobbies and interests. People involved in caring for the person

Blogs I'm watching by Mark Ivory

Dementia UK's website gives some useful tips on the phenomenon of "sundowning," which it describes as "changes in behaviour that occur in the evening, around dusk." Various reasons have been given for these signs of agitation, aggression or confusion late in the day, although none appears to be conclusive. Tiredness and a sense of being in the wrong place as darkness falls are among those mentioned in the Dementia UK article, while other explanations include too little or too much light, medication side-effects, and "body clock" disturbances caused by neurophysiological alteration in the brain. Of course, the danger is that by bundling up these time-sensitive dementia symptoms and giving them a name we fail to act on them: "Oh, don't worry, it's just sundowning" wouldn't win any friends in the CQC. Sometimes the phenomenon occurs because medication is wearing off and Dementia UK says that hunger, thirst and physical pain can play a part. Obviously, all these things deserve a response in their own right and with this in mind the article offers a list of practical tips, one of which is "ask the person what is the matter – listen carefully to the response and, if possible, see if you can deal with the source of their distress." Surely sound advice. And in my view the final tip would appeal on a personal level to most people as it certainly does to me: "Introduce an evening routine with activities the person enjoys, such as watching a favourite programme, listening to music, stroking a pet etc. Try to keep television or radio stations set to something calming and relatively quiet

however. Sudden loud noises or people shouting can be distressing for a person with dementia."

www.dementiauk.org/sundowning-changes-in-behaviour-at-dusk

Prominent American Maria Shriver (she of the Kennedy family) is founder of the Women's Alzheimer's Movement, dedicated to "finding out why Alzheimer's discriminates against women." Every 66 seconds a new brain develops Alzheimer's and two-thirds of them belong to women, says the website, before hastening to point out that women also make up two-thirds of all caregivers. "Women are at the epicenter of the Alzheimer's crisis – that's why we must be at the heart of the solution," Shriver is quoted as saying. It's serious stuff, but leavened with a little light-heartedness or "Alzhumor" as Maria Deneau's blog on the site calls it. It's about using laughter to lighten the mood of caregiving, she says, adding: "I've started noticing that the conversation around Alzheimer's disease is always so heavy. Like, dead weight heavy. It's about time we started changing that tone – especially for the folks and families doing the caregiving." She lists three "Alzhumor coping strategies," the last of which (to take an example at random) is headed "Hallucinations are Normal, Don't Argue". A former pig farmer repeatedly hallucinates pigs running through the house and his children have no idea what to do about it. Eventually, in despair, they make an enormous drama of pretending to chase the pigs out of the house - and it works. "About damned time somebody listened to me," says their father, before settling down quietly for the evening. Deneau sums up: "My biggest takeaway here is to just keep it light as much as possible. If it's funny, LAUGH! If it's not

funny, LAUGH... I'm certainly not trying to 'make light' of the horrors of this disease, but to encourage you to 'be light' when going through your day."

<http://thewomensalzheimersmovement.org/alzheimers-humor-maria-deneau/>

Closer to home, the *Caring Times* blog reminds us of further woes from which we might seek escape into jollity. Theresa May's pre-election travails over social care were as nothing compared with the NHS's battle to secure beds for hospital discharge purposes at any price. Or so it seems if guest blogger Bob Ferguson is any guide. Local tensions between health and social care sometimes erupt into outright hostility as one hospital's attempt to combat delayed discharges illustrates. "It mounted a predatory raid on capacity normally contracted by the local authority for ongoing care, securing beds for step-down purposes by the simple expedient of overpaying," Ferguson says. "Its comeuppance for this aggressive procurement came subsequently when residents were stranded by the resultant reduction in council-funded accommodation for long-term usage." Whatever happened to the peace and harmony promised by the Better Care Fund? Gone with the wind, it seems. Ferguson adds: "Health and social care bodies have a well-developed tendency to act unilaterally. A makeshift inducement [like the BCF] will be unlikely to persuade them to shed that skin. If they come under pressure, they will do whatever it takes to hit their targets – like taking impromptu action to uncork momentary bottlenecks in the discharge process." If you live and work in the wrong place, it's still dog eat dog out there.

www.careinfo.org/an-upgraded-better-care-fund-game-changing-or-game-playing

who inputs their life story into the app will also be able to find out about any fears the individual may have and avoid any conversations, situations or activities that could trigger those fears. For further information, go to www.myjustincaseapp.com

Two new DVDs have been produced by the National Council for Palliative Care (NCPC) as an aid to understanding the Mental Capacity Act (MCA). One covers **Best Interests Meeting** and the other **Advance Care Planning**, breaking down the principles and procedures into clear steps, according to the NCPC. More information at www.ncpc.org.uk

The Care Inspectorate in Scotland has launched a guide to help family and friends of people living in care homes to make the most of the time

spent together. Called **Come On In: Staying connected**, the booklet is specifically designed to help families overcome barriers that can materialise when a loved one with dementia moves into care. Produced with the Campbell Snowden House care home in Inverclyde and Scottish Care, the handy guide is intended to make a care home visit enjoyable and engaging. Heather Edwards, the Care Inspectorate's dementia consultant, said: "We know that maintaining close relationships with loved ones is really important for the wellbeing of people living in care, particularly those living with dementia. But we also know from our experience, and the experience of the care providers we work with, that it can sometimes be difficult for people to adjust to visiting their loved ones in a new setting." Guide available free at www.careinspectorate.com

A new app based on a database called **IRIDIS** will assess the suitability of a building's physical environment for a person with dementia. The free app, from Stirling University's Dementia Services Development Centre (DSDC), is designed to help improve workplaces, public buildings and homes for people with dementia. It promises to provide a digital assessment of how suitable a residence, care facility or other environment is in terms of the physical aspects of design, including lighting, colour contrast and noise, evaluating their impact on the person's quality of life and ability to live independently. The app, which will be available in the autumn, has been developed with construction experts Space Group. Go to www.spacegroup.co.uk

Construction of a new **dementia-friendly home** aimed at learning how to

improve support for people living with the condition will begin on the BRE Innovation Park in Watford this autumn. Adapted to cater for different types and stages of dementia, the 100 square metre house has been designed by researchers from Loughborough University and building science centre BRE. It will act as a show home and give developers, care providers and families an opportunity to learn about better ways to equip a home to help people with dementia. Features will include: clear lines of sight and colour-coded paths through the home that help guide people towards each specific room; increased natural lighting, helping people stay alert during the day and to sleep better at night; noise reduction features to lower the chances of stress; and simple switches and heating controls, with safety sensors in high risk areas such as the kitchen. More information at www.lboro.ac.uk and www.bre.co.uk

Events

- 11 July
Next steps for older people's care
 Morning conference in Cardiff looking at the Welsh dementia strategy and new models of care. For details go to www.policyforumforwales.co.uk
- 12 July
A Future Vision for Adult Social Care in England
 In the context of new government funding, the conference in London will consider emerging challenges. More details at www.policy-uk.com
- 14 July
Delivering older people's care and managing frailty
 London seminar looking at funding, integration and standards. For information go to www.westminsterforumprojects.co.uk
- 16 – 20 July
Alzheimer's Association International Conference
 Being held in London this year, the conference will look at new findings in dementia science. Details at www.alz.org
- 14 – 15 September
Doing Dementia Design
 Liverpool conference to promote dementia-friendly principles in the design of all buildings, places and spaces. More information at www.DoingDementiaDesign.com
- 20 September
Best Practice in the Care Home Sector
Caring Times conference at the MAC Birmingham showcasing best practice, looking in particular at environment, innovation and technology. Details at www.careinfo.org/bestpractice
- 5 October
Annual Care Conference for Wales
 Leading speakers will take part in this Cardiff conference. More information soon at www.careinfo.org
- 10 – 11 October
Care Show
 Includes integrated care, dementia care practice and innovation in care. More information at www.careshow.co.uk
- 16 – 18 October
Alzheimer's Disease & Dementia
 International conference in Rome on advanced research and diagnostic approaches. See <http://alzheimers-dementia.conferenceseries.com>
- 25 October
Next steps for delivering the New Models of Care and vanguard sites
 Morning seminar in London including evaluating the potential of social prescribing in care provision. Go to www.westminsterforumprojects.co.uk
- 2 November
The future for adult social care in England: funding, integration and workforce challenges
 Morning seminar with CQC chief inspector Andrea Sutcliffe among the speakers. For agenda and booking go to www.westminsterforumprojects.co.uk
- 7 – 9 November
12th UK Dementia Congress
 Held at Doncaster Racecourse, UKDC will offer a huge array of debates, workshops and networking opportunities, plus an exhibition. See www.careinfo.org/ukdc-2017
- 9 November
National Dementia Care Awards 2017
 Entries now open for these prestigious annual Awards, culminating in a celebration dinner at the historic Doncaster Racecourse. Deadline for entries is 21 July. Enter online at www.careinfo.org/dementiacareawards-2017
- 24 November
National Care Awards 2017
 Awards presentation dinner at the Hilton London Metropole. To enter (by July 21) go to www.careinfo.org/awards-2017
- 29 November
The Future of Ageing 2017: Transforming Tomorrow Today
 ILC-UK London conference aims to challenge and energise delegates to bring about the change needed for an ageing population. Details at www.futureofageing.org.uk

More information on JDC/Hawker conferences at: www.careinfo.org/events or tel 020 7720 2108 ext 204, or email events@hawkerpublications.com