

Blogs I'm watching by Mark Ivory

Kate Swaffer's blog from Australia has always been well worth reading, so more's the pity that Kate no longer blogs every day in the way she did. Disturbingly, she says in a recent instalment that she's been personally and publicly attacked over the last few months and has not had "the capacity to function (paddle) like I used to." Thanks to what she describes as this hideous experience a variety of projects have been put on hold, except for writing poetry. Writing poetry is, she says, "a gift from dementia" and has become part of her life. So, while promoting a poetry competition from the Adelaide Plains Poets, she shares this one with her readers:

Daring and dangerous
I'm trying to come back
After a very rough ride
On the waves of
Personal destruction
Finally understanding
Who are friends
And who are really foes
Holding onto
Those I love and who matter
<https://kateswaffer.com/2017>

Bereavement and loss are universal but have a unique impact in the case of dementia. Sian Blackham, discussing how Alzheimer's Society Cymru and Cruse Bereavement Care Cymru are collaborating on a new project, points out that some people may experience feelings of loss and grief even before diagnosis as symptoms appear. "People with dementia, and those close to them, can experience bereavement at different stages from diagnosis through to a person's death, and beyond," she says. The new project is funded by the Welsh government and is being delivered across Wales by specially trained volunteers providing face-to-face and telephone support for people affected by dementia who are bereaved. Training in bereavement support and dementia awareness is also on offer to care homes, hospices, hospitals and other health and social care settings along with a resource pack. But more volunteers are needed! If you're up for the challenge, contact project manager Maxine Norrish at maxine.norrish@cruse.org.uk. Or, for those who live in Wales and are affected by dementia or bereaved, they can either refer themselves or be referred to what is surely an invaluable service.
<https://blog.alzheimers.org.uk/dementia-insight/wales-bereavement>

New drugs offered on prescription by NHS doctors first have to be assessed by the National Institute for Health and Clinical Excellence (NICE) for cost-effectiveness. Failing the NICE test is nasty news for drug companies whose

treatment can't then be offered through the NHS and sometimes for patients too who can't afford the drug unless it is available on prescription. Not that any of this has had a direct impact on dementia patients, who are still awaiting discovery of a long-promised treatment (although, of course, there are drugs for symptom management). But now there is a second hurdle that could more easily trip up future treatments for dementia, a new "budget impact test" which will also have to be passed by drugs even when they have been deemed cost effective by NICE. It has certainly caused a stir at Alzheimer's Research UK (ARUK), where Clare Van Lynden blogs that, if a new drug costs more than £20 million a year and talks with the pharma company fail to secure a better deal, NHS England may be able to delay its introduction. She says: "Our concern is about what could happen when a breakthrough drug for dementia is discovered. One of the main criticisms of the budget impact test has been that treatments with the potential to help large numbers of people would be more likely to be affected, as these will also mean a bigger cost to the NHS. With so many people living with dementia, future treatments for the condition could fall into this category."

ARUK, which is heavily invested in drug discovery, thinks it has a better solution: an early warning system alerting the NHS to new treatments on the horizon. Then those all-important talks could begin much sooner and any unpleasant surprises could be averted.

www.dementiablog.org/budget-impact-test