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In Praise of Dignity and Appropriate Dementia Care

White Paper

Susan Kurrle, January 2020

Introduction

Susan Kurrle has been connected to loved ones with dementia since she was a child, which she says makes the condition kind of normal in her life. She has also been a practising geriatrician for more than 30 years, working in both hospital and community settings. The University of Sydney Professor in Health Care of Older People and Director of the NHMRC Cognitive Decline Partnership Centre, kindly shares insights from her research and clinical experience.

EVIDENCE-BASED GUIDELINES TO USE

I'm a firm believer that any doctor, nurse, pharmacist or allied health professional who supports people with dementia should have a copy of the Clinical Practice Guidelines for Dementia on their desk or a link to them on their computer.

The guidelines are freely available and cover appropriate medication, management of behavioural and psychological symptoms, palliative care, the language we use and the advice we give.

We put many hours of work into developing the guidelines to ensure they are evidence-based, practical and achievable, and draw on international best practice with input from clinicians, aged-care providers and consumers.

Most of us know about the principles of dignity and care. They are upfront in the guidelines because we feel they are equally important to the evidence. Anyone who has not read the principles of dignity and care should please do so.

When last did you hear a colleague use the word demented? It makes me cringe, but it still happens. Consumers care deeply about the language we use, which is why the section on dementia-friendly language is so important. It's one of those little things that make a big difference to people.

Here are a few other points from the guidelines that are valuable to know:

- It's a myth that memory problems are a normal part of ageing. We must explore concerns or symptoms when a patient or their carer first raises them.
- People with dementia who develop behavioural and psychological symptoms of dementia should usually be treated using non-pharmacological approaches in the first instance. If pharmacological management is used, this complements, not replaces, non-pharmacological approaches.
- There's evidence for trialling a selective serotonin reuptake inhibitor anti-depressant (SSRI) for agitation in dementia if non-pharmacological treatments are inappropriate or have failed. Another approach may be to manage pain that may be present.
- People living with dementia in the community need to be offered occupational therapy interventions and an exercise program.
- We need to provide information to people with dementia and their carers about how to join a support group.
- Everyone working with patients needs to receive appropriate training in dementia care and be taught how to communicate clearly with people with dementia, their carers and family, and to provide person-centred care. I recommend having a look at the free Massive Open Online Course from the University of Tasmania and the Wicking Institute, available for all levels.

PLAYING TO OUR STRENGTHS

Something that has made a fantastic difference to many of my patients is the Care of Older Persons in their Environment (COPE) program.

It is a structured 12-week occupational therapy and nursing intervention designed to assist people with dementia and their carers to independently manage everyday activities.

With COPE, occupational therapists and nurses teach the person with dementia and their carer how to play to their strengths and manage at home.

It reduces dependency, increases engagement and helps to keep people at home for as long as possible.

An example of an insight from the COPE program:

> ***It's best not to contradict someone with dementia when they make an error. For example, saying its Wednesday when its actually Saturday. Simply change the subject.***

Seven Essential Principles

It's getting better, but there's still lots of room for improvement in the way people in hospitals are looked after if they become confused.

In 2011 the NHMRC Cognitive Decline Partnership Centre piloted a program called Care of Confused Hospitalised Older Persons (CHOPs).

There are seven principles that have been shown to improve the identification of dementia. We have not yet studied outcomes such as reduced length of stay or repeat admissions.

The first principle is that all patients aged 65 and older must be screened for confusion on admission or within 24 hours of admission using a validated screening tool.

Another example is as simple as it is important: Hospitals must provide a supportive care environment for older people with confusion.

Strategies to orientate older people and minimise confusion include:

- Clear signage, in contrasting colours;
- Minimising noise and hustle;
- Positioning familiar items around the bed area to create a warm and friendly atmosphere; and
- Ensuring toilet doors are painted with an identifiable colour, toilet seats are a contrasting colour to the toilet and illustrating ward signs with pictures.

The other principles emphasise the need to assess and prevent delirium risk, manage confusion, train staff and have appropriate measures in place to ensure patient-centred care.

> ***So far, the principles have been adopted by 13 hospitals across NSW and are starting to be adopted into Victoria, Queensland and several hospitals in Germany.***

FRAILTY CAN BE REVERSIBLE

Frailty is a state of weakness, exhaustion and slowness. It is difficult to define, but we know what it is when we see it.

It was once thought to be a transition to ill health and death. However, it can be reduced and even reversed with physiotherapy and appropriate nutrition.

We conducted a randomised controlled trial in 2010-11 that used exercise and nutrition to address physical frailty.

Participants were also asked what they wanted to achieve. Their responses included that they wanted to be able to:

- Catch a train again;
- Go to book club;
- Go to religious services; or
- Look after the grandchildren.

Following the trial, almost everyone in the intervention group improved their strength, walking speed and achieved their goals.

A Touching Story Of Intergenerational Care

Earlier this year, Professor Susan Kurrle helped to capture the imagination of families across Australia as the senior geriatrician on the ABC documentary series Old People's Home for 4-Year-Olds, a touching social experiment involving older people and pre-school children.

The program was an example of intergenerational care, and I would like to see it become even more mainstream. The idea is that you bring different generations together to participate in activities that are beneficial to both.

It is not just children coming and singing a Christmas song once a year. These were formal and regular activities that included gardening, art, walks and informal interaction.

Both generations derived significant benefit and learned from each other.

We know from the evidence that intergenerational care has a positive impact on older people's health and improves mood, which is something we saw during the program.

The results were terrific, with overall clinically and statistically significant improvement in all primary outcome measures for the older participants, all of whom lived in supported care.

These outcomes included walking speed, handgrip strength, balance and improvement on the Geriatric Depression Scale.

Importantly, the effect was sustained for over 10 months in many participants.

Click here to watch the series online.

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