The dementia care pathway

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Outline of presentation

• Introduction: what is dementia; numbers
• Living with dementia and need for a dementia care pathway
• Time points along a dementia care pathway

Data:
• Using data from review paper
• And qualitative findings from some of our department’s dementia research
What is dementia?

- Long term progressive disorder
- 1 in 3 over 65 predicted to die with the condition

- Short term memory, orientation, comprehension
- Decline in reasoning, communication skills
- Behavioural problems – aggression, agitation, wandering

- Emotional changes – mood swings, irritability, depression, anxiety
- Deterioration in carrying out activities of daily life
Numbers of people with dementia

• Growing numbers of people with dementia worldwide has recently attracted global interest

  2010: 36 million people living with dementia
  2030: 66 million
  2050: 115 million

• Expensive disease on the public purse – total worldwide costs of dementia estimated to be US $64 billion

• Governments worldwide committed to sharing systematic approaches for preventing, diagnosing, and treating dementia: Australia, England, France, the Netherlands, Canada, Norway, USA, Finland, Republic of Korea

• World Dementia Council was launched in 2014 following the G8 summit in 2013 in London, UK
Living with dementia

• Typified by confusion and anxiety – worry about onset of memory problems, when it might get worse, when to seek help etc.

• Uncertain disease trajectory, unclear prognosis and lack of clarity about symptoms
Living with dementia

• Our research over past 5-6 years has focused on numerous aspects of living with dementia
• Gaps in understanding the patient journey –
  Transition from worrying about your memory – to first service encounters – to receiving a diagnosis of dementia
• And longer-term impact of this
Would a dementia care pathway help?
What is a dementia care pathway?

• Patient’s route into services and choices of support and treatment

• “Journey”, “roadmap” and “labyrinth” often used
  • Associated imagery of “barriers and facilitators” and “signposts”

• Impression of clarity and certainty suggested by term “pathway” can be attractive to patients
Time points along the dementia care pathway

- Early symptom identification and first service encounters
- Assessment process
- Diagnostic disclosure
- Post-diagnostic support and appropriate interventions
## Early symptom identification and first service encounters

- Memory problems most common reason
- Other triggers: emergency care, hospitalization, or bereavement
- Barriers: lack of awareness, pervasive cultural attitudes, “not ageing”
- First point of call was primary care physician (or General Practitioner)
- Family members often instrumental in seeking help
- How GP handles early questions seem to be crucial in patients’ quests for answers and how these are handled can alleviate anxiety and distress among patients worried about their symptoms and among their caregivers
And I kept saying to the doctors, there’s something wrong, there’s something wrong and eventually, this year, they actually referred me but it took quite a few months to get an appointment which came a few weeks ago, um, and now we’re just waiting for a scan. I’d been in so many times and said there’s something happening and because they couldn’t see it, they took a couple of blood tests. Well, to me, you can’t tell on blood tests and I said “listen”, you know, “you’ve fobbed me off with blood tests, I want something doing”.

(PwMP: S2-5.1)
• Visiting a memory clinic for assessment can be daunting and frightening
• Anxiety and confusion common
  • Many talked of “entering a labyrinth,” with no signs or markers about what would happen or when
• Long waiting times, limited knowledge about where to turn for further information and advice
• Anxiety during memory tests, little reassurance from practitioners
• Scores on tests were meaningless – didn’t always know what tests represented
• Clarity, explanation and management of expectations lacking, and might have helped
It’s just the not knowing if it is something that’s wrong with you, or if it is just forgetfulness. Yes because I’m waiting, I don’t know whether it’s going to take. ... Well, it’s like a fortnight, isn’t it, I think it is since I last went. So how long is it going to...? Will all the appointments be over a short period of time or will they be spaced out over a long period? If you knew how long it’s going to maybe drag on for. Just the waiting, I suppose. (PwMP: S2-8.1)
• Process, rather than one-off event – series of meetings to give time for patients and carers to address any questions and concerns
• Discussion of possibility of dementia before confirmed diagnosis might help – diagnosis less shocking

• Impact can be **positive** – relief, closure; opportunity to adjust and accommodate changes
• Or **negative** – distressing, anger, frustration, denial, overwhelming sense of loss

• Impact on caregivers too
  • Changes to roles and relationships, and growing dependence from relative with dementia
  • Can impact on health and well-being of caregivers too

• Process of disclosing diagnosis needs to be handled with skill, forthrightness, sensitivity, patience, and a person-centered approach
Absolutely devastating. And for a week after that neither of us said very much of anything at all. You eventually get things back into perspective as much as you can, but it is not a good way to do it. It really isn’t. If you are examining the process of this then it needs looking at. Yes, we were invited to express concerns and satisfy curiosity, but it’s a blow. You are absolutely punch drunk. You don’t think straight. (Carer: S2-1.)
• Post-diagnostic support depends on specific dementia type and stage
• Alzheimer’s Disease receive acetylcholinesterase inhibitors
• Those with Mild Cognitive Impairment and vascular dementia receive no support – asked to return in a year’s time to a memory service or if symptoms appear to worsen
• Growing public expectation that all diagnoses of dementia bring entitlement to medication – resulting in disappointed expectations

• Psychosocial interventions growing – e.g. cognitive stimulation therapy and reminiscence therapy
• Demand for advice, social networks, and community and peer support high
• Information from voluntary or third-sector organizations is also valued
They've said they think there's nothing they can do. And they don’t... They haven’t actually given exactly a diagnosis. They’ve said it could be, erm, what do you call it – you know, lack of supply of blood to the brain. And that’s... that’s it, basically, at the moment. [following probed question]. No, they are not following it up. Well, they are not following it up, as far as I know. They’ve just said that they think that if they’d have seen my mum a few years ago, they might have been able to do something. But they think they can’t now. (Carer: S2-3)
Are pathways the solution to achieving clarity?

- Dementia care pathway is not straightforward
- First service encounters depend upon relationship with GP, how persistent the person is, carers’ involvement
- Referral route to specialist care may vary
- Brief conversation during assessment regarding what individuals want in terms of how they are assessed, referred, and diagnosed and co-morbidities they have may have
- Refer to “pathway” with caution as it promises more certainty than is possible
Disclosure and Disclaimer:
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THANK YOU FOR LISTENING!