

## Living Better with Dementia - Shibley Rahman

Chapter	Subject Matter	Content	Experience
Chapter 1	Strategy/Policy	<p>Prevention Risk Factors:</p> <ul style="list-style-type: none"> <li>• Depression</li> <li>• Lack of Social Network</li> <li>• Lack of education</li> <li>• Vascular problems</li> <li>• Overweight</li> <li>• Diet</li> <li>• Health inequalities</li> </ul> <p>Need for H &amp; SC to work together to develop joint policies and deliver them</p>	<ul style="list-style-type: none"> <li>• G presented with depression before diagnosis of Dementia</li> <li>• All of G's close friends had died</li> <li>• Lifelong distrust of others</li> <li>• High blood pressure</li> <li>• Overweight</li> <li>• Ricketts as a child</li> </ul> <p><u>Comment</u> H &amp; SC working together along with family around the person at risk would produce the most positive results</p>
Chapter 2	Stigma, Citizenship	<p>Stigmatic effect of diagnostic labels created by media etc.</p> <p>Place of diagnosis</p>	<p>G's diagnosis was given in a building she knew held Mental health services. She was upset and wanted to leave (fear!)</p> <p>Before the diagnosis, G warned family that something was happening to her that none of her family had experienced and that because of it, she would no longer be able to help anyone.</p> <p><u>Comment</u> Although Media coverage of 'Alzheimer's disease' has raised awareness of dementia which will be helpful for the younger generation, the older generation, still feel the stigma of mental health and are unlikely to ask for help in the early stages for fear of confirmation of their worst fears.</p>
Chapter 3	Culture & Diversity	Cultural Diversity in Caregiving	G presented late for diagnosis following carer realisation that 'something was

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		<p>Carers in BAME communities in contrast to White communities</p> <p>Patients supported for longer in the community by their families leads to late diagnosis, usually when the patients reaches crisis point and the carers can't cope.</p>	<p>wrong'. Crisis point happened shortly after this.....</p> <p><u>Comment</u> Agree; families, friends etc. can keep people going for long periods of time, but eventually help will be required by H &amp; SC.</p>
Chapter 4	Global Strategies	<p>Acknowledges differences in organisation and function of global healthcare systems and how they deal with dementia.</p> <p>A move away from Pharma solutions to maintaining independence &amp; wellbeing via a range of care givers with different activities of daily living across each stage of dementia.</p> <p>Opportunity cost of informal care provided by family &amp; friends &amp; residential care.</p> <p><i>'The quality of life of family carers directly impacts on the quality of life of people living with dementia'</i></p> <p>Move from medical model (incurable</p>	<p>G's carers had to be proactive, contacting the individual help lines to get support. Everyone was helpful but they weren't joined up which created strain on carers.</p> <p><u>Comment</u> In the UK carers navigate with the help of SSD but this only deals with the Social needs. When crisis point is reached, it's Health services that are required with SSD supporting discharge and onward placement.</p>

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		<p>illness) to emphasis of living well with dementia and Person centred care.</p> <p>Common to all countries is the difficulty for carers/patients in being able to 'navigate' the system. A more integrated system is required.</p>	
Chapter 5	Young onset Dementia	<p>Early diagnosis problematic but crucial to receiving H &amp; SC support.</p> <p>Education &amp; Occupation – patients with a high level of education and occupation can cope better with cognitive functions</p> <p>Need for BIG DATA &amp; personalised meds but no money to deliver this</p>	<p>Late diagnosis with no immediate support meant carers had to 'do everything'</p> <p><u>Comment</u> Not convinced this is the case. It may delay the effects. However University lecturer has lost ability to communicate. Head teacher requires 1:1 nursing re violence and aggression. Everyone no matter whether they are educated or not, finds a way to cope with the disease. Irrespective of the type of dementia, there are basic 'personality' characteristics that exist. So a person who has been in a position of authority, still tries to organise people etc.</p>
Chapter 6	Delirium	Importance of Community & Support Networks	...
Chapter 7	Care & Support Networks	Person centred care.	<p>All care providers (MH Trust, SSD) have tended to exclude G because of lack of mental capacity. Persuasion tactics have to be used to gain cooperation. Tendency to work with carers because it's easier.</p> <p>Within care home environment, they recognise how helpful family/carer involvement in helping them look after G.</p>
Chapter 8	Eating & Living Better	Eating as a Social Activity and core aspect of person centred care.	<p>Nutrition standards are high in care home but they are challenged to find food the residents will eat. They have to cater for everyone!</p> <p>Mealtime environment is good (tablecloths, white plates etc.)</p>

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Chapter 9	Incontinence	<p>Cognition and Incontinence linked.</p> <p>Maintaining hygiene</p> <p>Managing incontinence pre/post diagnosis</p>	<p>Continence issue recognised a year before diagnosis for G.</p> <p>Non compliance with bathing post diagnosis although still washes.</p> <p><u>Comment</u> Personal hygiene habits are difficult to address so this is a challenging area for services and carers to deal with when trying to support the individual to maintain independence.</p>
Chapter 10	Whole Person Care	<p>Relevance of Person Centred Care to the individual</p> <p>Person vs patient centred discussion. Stigmatising attitudes of hc professional and service providers can lead to lack of support for self management.</p> <p>Education for public and professionals required.</p> <p>Various thoughts on person-centred care and strategies for its promotion once of which is the 'avoidance of routines'. (p 198).</p> <p>Conflicting views of what good Patient centred care is.</p> <p>Kaufmann and Engel (2014) study finds</p>	<p>Routine was the one thing that kept G on track and helped G and carers to cope with situation</p> <p>Family members in denial for period of time and unhappy with the speed at which intervention took place following crisis point.</p> <p><u>Comment</u> As the family/cares are likely to be able to fill in the memory gaps for the individual in terms of advising healthcare professionals, more support for them should be given and the diagnosis stage.</p>

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		<p>that individuals with dementia are potentially important informants of their subjective wellbeing.</p> <p>Cassel describes the facets of a person has having:</p> <ul style="list-style-type: none"> <li>• a past</li> <li>• a cultural background</li> <li>• roles &amp; relationships with others</li> <li>• being political and doing things, including action and creation</li> </ul> <p>Family relationship – conflict seen in mild to moderate dementia cases. Themes include:</p> <ul style="list-style-type: none"> <li>• accusations of neglect</li> <li>• exploitation</li> <li>• lack of communication</li> <li>• sequestration of the person with dementia (hiding away)</li> </ul> <p>Supportive families can aid self care.</p> <p>Patient centred care – sharing decisions rather than the old style paternalistic way.</p>	
Chapter 11	Inequalities – Focus on Housing	<p>Housing as a key determinant of Health.</p> <p>Extra Care Housing initiatives to include people with dementia</p>	<p>G had been living in her own home with no social network, because all of her friends had died and family had moved away and were infrequent visitors. The move to a care home following an inpatient saw the introduction of meaningful daytime activities and company to aid brain function.</p>

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		Ability to socialise wherever a person is housed.	<u>Comment</u> The Extra Care Housing is fine provided there are the support networks in place and a Plan B for when the individual's condition deteriorates.
Chapter 12	GPS Tracking	Ethical considerations  Wandering, getting lost  Consent  Human Rights  Personal Budgets to give choice and control or rights based approaches.	This was not an option for G. The most on offer was a sensor device for in the home that was being piloted by the local authority. G was a wander and went missing. If she'd had a GPS tracker she would have been found sooner.  <u>Comment</u> Rights based approaches would seem to be more appropriate as introducing personal budgets to people with dementia just adds to their confusion and is likely to mean more admin for care managers.
Chapter 13	Rights-Based Approaches, Personal budgets	Nuffield Trust – argues bringing health and SSD budgets together around the individual makes most sense.  Barriers to implementation of personal budgets for people with dementia.  Scotland Act 1998 – promotes human rights of all people with dementia and their carers. (p272)	As an inpatient and then care home resident, the issue of personal budgets didn't enter the discussion. G was unable to make her own decisions and looked to family members to make them for her.  Mental Capacity was tested at various stages of care with a 'risk-based' approach.  <u>Comment</u> The process of testing mental capacity was onerous and somewhat demeaning. There must be a better way.....

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		<p>Mental Capacity Act (2005) implemented by some as a more 'risk-based' approach .</p> <p>Dignity = key concept to living well with dementia but various interpretations of Dignity (p277)</p>	
Chapter 14	Art Music & Creativity	<p>Breaking down barriers through art forms.</p> <p>Providing a sense of purpose/belonging.</p>	<p>Music is very important to G's daily life now. She constantly asks when the music session is due to take place. She remembers the words and sings along with the group. Her memory of happy times visiting the theatre, who she saw, who she went with are all associated.</p>
Chapter 15	Sporting Memories	<p>Declarative memory:</p> <p>Episodic = recall of personal facts Semantic = recall of general facts</p> <p>People living with Alzheimer type dementia find it easier to deal with old memories than what happened yesterday</p> <p>The brain has a particular approach to football memory (p308) with emotion recall of events leading to vivid personal memories.</p> <p>Faces represent the stimuli we rely on for social interaction.</p>	<p>Perhaps comparison can be made to rare visits from family and friends, where G recalls emotions linked to events and these people.</p> <p>The people G sees all the time, she recognises, and links them to their family etc.</p>
Chapter 16	Innovation,	Reducing inappropriate use of	G is on Aricept to manage symptoms. Care for G is more about provision of

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	Antipsychotics	antipsychotics.	meaningful daytime activities, diet and company.
Chapter 17	Promoting Leadership	<p>G7 Dementia Leaders promised treatment or cure by 2025. Whilst this shouldn't have been promised it has made the NHS and Social Care systems look at the sort of care they should be providing.</p> <p>Recognition that there are no books on leadership for people living better with dementia.</p> <p>Future leaders on Dementia will not come from traditional training routes.</p> <p>The author argues for people living with dementia and their carers to have a key role in leading changes to policy in a whole systems approach.</p>	<p><u>Comment</u></p> <p>Whose role will it be to bring all the parties (Health, SSD, Voluntary Sector) together including the people living with dementia and their carers?</p>
Conclusion	Conclusion	<p>All negative perceptions of Dementia will never be completely extinguished.</p> <p>Imperative for communities and society to be inclusive of people with dementia whilst allowing for individuals to choose for themselves.</p>	<p><u>Comment</u></p> <p>Communities are not always willing to include people with dementia and the tendency is to take control and not allow the person to make their own decisions, even when they are capable of doing so.</p> <p>There was no mention of the role of the voluntary sector providing support within the community. Too unreliable?</p>



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	<p>Emphasis should be on what the person can do, not what they can't.</p> <p>Right of timely diagnosis and post diagnosis support.</p> <p>Importance of diet.</p> <p>Changing the language used by scientists and practitioners e.g. 'wanderer'</p> <p>Opportunities should be given to people with dementia to lead change.</p> <p>Recognition that innovation in service provision is what is required.</p> <p>Less use of antipsychotics and more clinical nurse specialists.</p>	<p>Inclusion of people with Dementia in leading change is difficult to do beyond the early diagnosis stage. This is acknowledged particularly for patients with Alzheimer's.</p> <p>This text provides an excellent review of the research available on the subject of Dementia with key pointers for healthcare professionals to consider when implementing the necessary changes to care of people with Dementia.</p> <p>As it stands it will be helpful for the recently diagnosed educated individual, but for those less educated or informed, they will be looking for something much more basic in terms of the style in which it is written. They won't want to be steered to further reading but will be looking for all the answers in one text.</p> <p>Fundamental to all care provided is the need for Safety First for the individual. Once safe, with a good diet and the basics of human kindness in terms of family, support networks or a care home with meaningful daytime activities, they are in a good position to maintain a level of dignity and live better with Dementia.</p>
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