

Health and Ageing Committee to Inquire into Dementia Early Diagnosis and Intervention

Improve quality of life and assist people with dementia to remain independent for as long as possible

- Health promotion and prevention community programmes focusing on the two of the most important aspects of health:
 - nutrition and
 - physical activity.
- Telephone support:
 - better promotion of telephone support lines;
 - ensure telephone helpline have practitioners with local knowledge about services and
 - counselling helpline focus (instead of 'fix-it' approach where practitioners on the telephone practitioners focuses on commending a referral to the caller).
- NBN and/ or iPad technology:
 - interactive learning resources for individuals living with dementia and family carers and
 - video conferences with practitioners, for example, a GP appointment.
- Respite care:
 - scheduled stays throughout the year (similar to how it is organised in the UK) to make use of the unused residential aged care facility places.
- Day care services:
 - specialist early stage services to reduce wide range of needs trying to met within one service;
 - include counselling and
 - activity therapy.
- Different funding allocations for aged care placements:
 - a higher proportion of community care packages and a reduction in the proportion of residential aged care places (to reduce waiting lists for community care packages).
- Driving and dementia:
 - funding to evaluate a new novel Driving Dementia Decision Aid developed by the University of Wollongong to increase driving retirement in a supportive way among special needs groups and across geographical locations.
- Delirium:
 - funding to implement of the DoHA Delirium Care Pathways developed by the University of Wollongong across care settings and
 - ensure use of the Delirium Care Pathways audited during service accreditation.
- Memory clinics in community and hospital settings:
 - role: prevention, early diagnosis, health promotion and care management for individuals living with a dementia and their family carers;

- o international evidence demonstrates that specialist services are most effective, for example, for develop memory clinics for special needs groups.
 - o nurse led services: Practice Nurses, Clinical Nurse Specialists, Clinical Nurse Consultants and Nurse Practitioners delivering memory clinic services and
 - o settings: GP clinics, Dementia Advisory Services and within specialist medical services developing memory clinics.
- Dementia Advisory Service:
 - o providing higher a level and more intense intervention, for example, focus on formal counselling services, family therapy and enhanced knowledge and skills about treatment/ management options for early dementia interventions.
- Dementia Behaviour Management Advisory Service:
 - o enhanced promotion of their helpline because talking with colleagues we found that that non-DBMAS practitioners still do not immediately think of using the DBMAS telephone line as a source of help and support and
 - o formal counselling intervention added to the role (instead of 'fix-it' approach where practitioners on the telephone practitioners focuses on commending a referral to the caller) because practitioners tell us that the caller often knows what is best for the individual living with dementia who they are caring for but needs reassurance/ encouragement to continue on.
- Education for practitioners:
 - o more postgraduate qualifications among Practice Nurses, Dementia Advisory Service practitioners, Clinical Nurse Specialists, Clinical Nurse Consultants, for example, the fully distance work-based learning Graduate Certificate and Master of Science 'Dementia Care' at the University of Wollongong;
 - o capacity building with mentoring and role modelling, for example, clinical supervision, co-facilitation of education sessions with junior colleagues and holiday secondments by practitioners in DBMAS, Clinical Nurse Consultants and Nurse Practitioner roles and
 - o leadership and practice development skills for practitioners, for example, Graduate Certificate and Master of Science 'Health Leadership and Management' and 'Practice Development in Healthcare' at the University of Wollongong.
- Case management approach to the care of individuals living with a dementia and their families:
 - o focus on developing meaningful longterm relationships and
 - o focus on preventing problems (away from crisis management).
- Funded mentoring programmes for consumers and family carers:
 - o individuals living with dementia and their families matched with others who are paid to provide support and ongoing advice about living successfully with dementia.
- Target homelessness services:
 - o promote existing DTSC education and develop new DTSC resources for staff and volunteers in these services to better understand dementia.
- Target mental health services:
 - o promote existing DTSC education and develop new DTSC resources for staff in these services to better understand dementia.

- Implementation of DCRC research evidence:
 - Funding for practitioners to deliver evidence based therapies in the community and
 - DTSC to develop education initiatives for staff on how to deliver evidence based therapies in the community.
- Education for non-registered practitioners:
 - Certificate III to have more dementia content;
 - less emphasis on completing Frontline Management and an increased focus on completing dementia courses and
 - Certificate IV with a dedicated dementia focus;
 - creation of a Diploma in Dementia Care or Aged and Dementia Care and
 - creation of BSc in Dementia or Aged and Dementia Care (similar to Bradford Dementia Group in the UK).

Increase opportunities for continued social engagement and community participation for people with dementia

- All communities having a dementia cafe for social get together with support.
- Rural areas providing dementia camps with a range of activities for individuals living with a dementia and their family carers, for example, relaxation activities and thrilling adventure activities (for example the Extra Care Adventure breaks in the UK).
- Volunteering opportunities with mentors/ buddies for individuals living with dementia and/ or their family carers for purposeful and meaningful activities:
 - school lunch clubs;
 - Meals on Wheels;
 - Doing art work with children in day care and schools;
 - working op shops;
 - membership of Men's Sheds and
 - cafes in churches and op shops.
- Enhanced built environments in all areas:
 - commercial businesses, for example, coffee shops, hairdressers and newsagents beside day care facilities to encourage integration;
 - promote existing DTSC education and develop new DTSC resources for to city planners to better understand dementia;
 - promote existing DTSC education and develop new DTSC resources for council staff to better understand dementia and
 - children's playgrounds beside places where older people go, for example, the bowling or Leagues clubs and residential aged care facilities.
- Education and training for individuals living with a dementia and their family carers in the use of 'social networking' online environments to connect to local and wider communities.
- Promote DTSC education and develop new DTSC resources for University delivering Information Technology courses and commercial companies developing social networking media for staff to understand the potential market of individuals living with a dementia and their family carers.
- Mentoring to create life story books as web pages to deposit memories (similar to the project currently being undertaken at Monash University).

Help people with dementia and their carers plan for their futures, including organising their financial and legal affairs and preparing for longer-term or more intensive care requirements

- One-stop legal aid shops including decisions about homes and finances.
- Re-imbursements for solicitors to draw up guardianship and power of attorney documents to prevent unnecessary hospital admissions and presentations to guardianship boards when there is no legal documentation to prevent these.
- Promote existing DTSC resources and develop new DTSC resources for Guardianship Board staff to better understand dementia, in particular, that in the early stages of dementia individuals do have capacity to make decisions about many aspects of their lives.
- Promote existing DTSC resources and develop new DTSC resources for Universities offering law and financial degrees and relevant professional organisations to ensure better understanding about dementia among Solicitors and Accountants.

For example, “People on the guardianship tribunal and the appointed guardians often have poor understanding of dementia. Including assuming someone does not have capacity if they have a dementia diagnosis (even in the early stages) or not looking at their diagnosis in palliative terms, therefore requesting aggressive treatment. Other occasions we have needed to transport people living with advanced dementia and challenging behaviours to the tribunal hearings despite care staff requesting they do not attend as it will (and did) agitate the person.”

- Develop new set of Decision Aid Booklets (similar to the Driving Dementia Decision Aid developed by the University of Wollongong) early on during the dementia for use by individuals living with a dementia, their family carers and practitioners:
 - choosing person of choice to represent the individual living with a dementia in the future (prevent someone who the individual would not have been chosen being legally appointed);
 - changing location (geographical);
 - type of housing and
 - choice of care home in case this might be necessary.
- Re-imbursements for use of technology in the home.
- Adapting the home in advance:
 - choosing new technologies;
 - organising house to ensure day-to-day objects easier to find;
 - mind-your-mind programme to include learning how to use lists and
 - mind-your-mind programme to include learning how to use a calendar.
- Palliative care improvements:
 - easier access to specialist practitioners;
 - promote better understanding that dementia is a long term chronic illness and the dementia will require palliation and
 - promote DTSC education and develop new DTSC resources for practitioners working in palliative care.
- Legally recognise ‘contextual capacity’ for decision-making (similar to Europe) to ensure individuals living with a dementia not deemed ‘incompetent’ for all decisions and choices with each decision being assessed for its appropriateness for an individual living with a dementia to make.

How best to deliver awareness and communication on dementia and related services into the community

- National dementia helpline:
 - improved promotion of the helpline and
 - improved linkages to local and regional services from the national helpline.
- Raise awareness about workforce issues:
 - One colleague told us about her eight year old son, “My mum works with people who have lost their memory. My pop is just the same.”
- Television programmes and the media promoting dementia stories:
 - drama including individuals living with a dementia who are successfully engaging in the community with support and
 - newspaper articles about dementia and opinion pieces by practitioners academics.
- Use driving as issue to highlight how important it is.
- Using community resources:
 - local clubs holding presentations about dementia and
 - story time for children in day care or schools with individuals living with a dementia reading books or telling stories.
- Take the seriousness out of dementia and create humorous messages with a catchy double meaning.
- Focus on the facts that individuals living with dementia are most likely to live at home and have a long life with minimal interruption when effective support is provided.
- Campaigns with an early detection focus:
 - emphasise the expert knowledge of family and friends to detect when something is wrong before a professional would recognise it as dementia and
 - target family carers who think they have to cope with dementia because it is ‘part of ageing’ but it is not and help is available when a member of the family starts appearing confused as well as having difficulties with their memory.
 - Explain that family and friends do not ignore the strange things a person does because it could be the early signs of dementia.
- Help seeking campaigns:
 - highlight the need for help when dementia becomes difficult and troublesome because that is not normal and there is help available to provide support when problems occur and
 - emphasise the importance of seeking help before a crisis occurs because planning in absence of a crisis feels more manageable and less overwhelming and can help prevent a crisis.
- Use of the arts:
 - more children’s books like Mem Fox’s ‘Wilfred Gordon Partridge’;
 - regional schemes such as the one delivered in Canberra by Professor John Zeisel (visiting Professor at the University of Wollongong) to visit art galleries, poetry recitals and going to plays with individuals living with a dementia and their family members.
- Use of social networking media to create messages about the positive interventions available to live successfully with dementia for individuals and their families.

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