Dementia Behaviour Management Advisory Service (DBMAS) Vic.

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Frontotemporal Dementia
A toolkit for awareness, diagnosis and management
2011

Helping Australians with dementia, and their carers
Frontotemporal Dementia

A toolkit for awareness, diagnosis, and management
Commissioned by the Dementia Behaviour Management Advisory Service Victoria, part of the Australian Government’s Department of Health and Ageing Dementia Initiative.

Developed in collaboration with the Eastern Cognitive Disorders Clinic, Eastern Health Clinical School, Monash University, Box Hill, Victoria

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Preface

Frontotemporal dementia (FTD) is an unfamiliar condition to many health service providers and members of the public. Most people are familiar with the most common form of dementia, Alzheimer’s disease, and therefore tend to associate dementia with old age and memory loss.

FTD is a very different condition from the dementia associated with Alzheimer’s disease. It often presents confronting symptoms and unique management challenges at a much earlier time in life, generally between the ages of 45 and 65 years.

FTD is often thought to be a relatively rare form of dementia, though this perception may be due in part to the fact that it is not yet widely understood and may therefore be under-diagnosed. For this reason, many people with FTD and their families will experience a long and difficult journey before receiving a diagnosis and access to appropriate advice and support.

There is therefore a need to increase awareness about FTD amongst:

- People with early stage FTD and the families and friends who support them
- Health professionals involved in the diagnosis and management of people with dementia
- Services that provide care to people with dementia, including case managers, respite service providers, and home and residential care workers.
- Funding bodies and policy makers who establish programs that support people with dementia

This Frontotemporal Dementia Toolkit project was commissioned by the Dementia Behaviour Management Advisory Service Victoria and developed in collaboration with the Eastern Cognitive Disorders Clinic at Box Hill Hospital (ECDC; Eastern Health Clinical School, Monash University, Melbourne).
The aims of the toolkit are:

1. To provide current information about FTD. While not designed to represent a comprehensive literature review, the information presented herein was drawn from the most up to date research available at the date of completion.

2. To document available evidence-based strategies for effective management of the behavioural and psychological symptoms of FTD and, where there are gaps in existing literature, to offer further strategies based on the clinical expertise of a variety of specialist consultants.

3. To provide a comprehensive list of resources for assistance with a variety of diagnostic, financial, legal, emotional, and other issues which may arise for the target audience. Many of these resources are specific to Australia and to the needs of those residing in the state of Victoria. The majority of the toolkit content, however, is internationally relevant.

The toolkit is organised into a series of stand-alone modules. Accompanying power point presentations for the main modules will be due for release by the end of 2011. The modules are designed to provide accessible summary level information without overwhelming amounts of specialist detail. Presentations may be used to train health professionals or provide community information sessions. All modules include reference to scientific publications, websites, and other resources where indicated.

- **Module 1: What is frontotemporal dementia?** addresses the nature of FTD, provides descriptions of different clinical presentations, outlines a number of common symptoms, and provides basic information about the pathology and genetics of this condition.

- **Module 2: Diagnosing frontotemporal dementia** aims to assist health professionals in identifying and diagnosing FTD by highlighting helpful investigations and referral pathways.

- **Module 3: Why do we need a different approach in supporting people with FTD and their families/carers?** focuses on practical communication and behavioural management strategies.

- **Module 4: Assessing the impact of frontotemporal dementia** illustrates a person centred problem solving approach to assessing the impacts of FTD.

- **Module 5: Managing the impact of FTD disabilities and symptoms** gives detailed information and some suggested practical strategies for responding to the unique disabilities and symptoms of FTD.
• **Module 6: FTD as a young onset dementia: special considerations** describes issues unique to those who develop dementia earlier in life, including financial and legal ramifications and how to address these.

• **Module 7: Resources** section collates relevant resources under topical categories.

• **Module 8: References** section lists relevant scientific publications for further reading. This reference list is unique in its clinical focus and includes a wide range of articles addressing the nature, diagnosis, and management of FTD.

This toolkit may be accessed by health professionals or members of the general public via the ECDC website or by contacting DBMAS Victoria or ECDC directly. The toolkit will also be available on the DBMAS National website when this is launched.

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We sincerely hope this toolkit proves to be a valuable resource for health professionals and care workers, for those confronting FTD themselves, or for those who may be supporting a loved one with FTD. It is important for these individuals to know that specialist knowledge and assistance are available and that the journey with FTD does not have to be made alone.

We dedicate this toolkit to the founding members of FTD carer support groups in Australia. These carers have shown great bravery in coming together to share their stories. The experiences they have shared have been fundamental to our learning and it is their stories that will help to inform and ensure a smoother pathway for future FTD caregivers to come.