

COGNITIVE IMPAIRMENT SYMBOL: CREATING DEMENTIA FRIENDLY ORGANISATIONS

**A REPORT FOR ALZHEIMER'S AUSTRALIA
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FOREWORD



Over the last decade there has been a greater willingness to discuss the issues that dementia raises for all Australians than in the past.

Dementia is now a National Health Priority and new strategies are being put into place to improve quality of dementia care in both the health and aged care systems. Importantly, through Alzheimer's Australia, people with dementia are being empowered to speak out for themselves.

In spite of these positive developments, a diagnosis of dementia still results in stigma and social isolation, both for the person with the diagnosis and for their family carers. Australia needs new strategies if people with dementia are to feel included in our society and have the confidence to access health and other services like any other person.

One such strategy that consumers first raised at the Alzheimer's Australia 2005 National Consumer Summit is the idea of a cognitive impairment symbol. Consumers have advocated for an approach that could be used in both health and other organisations to identify a service that has staff trained to assist people with cognitive impairment.

The central feature of this approach is that the organisation involved makes a commitment to train and educate staff about dementia and on the best way to communicate with individuals who have a cognitive impairment. Alzheimer's Australia thinks this concept could work well in a range of organisations including hospitals, Centrelink and banks.

Since 2002, Ballarat Health Services in Victoria has done some wonderful work in using a symbol for cognitive impairment. The approach has been extended to more than 20 hospitals in Victoria and improved outcomes have been reported for consumers as well as health staff.

Initially we are hoping that the concept of the symbol and the obligation it places on organisations to be dementia friendly will be taken up in acute care; we know that there is all too often a failure to identify people with dementia or provide them with appropriate care and support.

In the longer term, we will work with other organisations that are prepared to make a commitment to be a dementia friendly organisation.

My thanks to the Alzheimer's Australia National Consumer Advisory Committee for their determination in getting this strategy into place. My thanks also to Glenn Rees, the CEO of Alzheimer's Australia, Dr Ellen Skladzien and Kristen Holdsworth for the work they have done to bring this document together.

A handwritten signature in black ink, appearing to read 'Ita Buttrose'.

Ita Buttrose AO, OBE
President, Alzheimer's Australia
May, 2013

FOREWORD

Alzheimer's Australia's National Consumer Advocacy Committee has advocated for a cognitive impairment symbol since the group began in 2005. We have lost none of our determination since that time to have the concept implemented.

Although progress has been slower than we hoped, we are pleased to see the release of this paper. Kristen Holdsworth and Dr Ellen Skladzien have worked hard in developing a paper that provides a comprehensive summary of how symbols have been used both in Australia and internationally to assist people with cognitive impairment and offers recommendations outlining the next steps for the implementation of a Cognitive Impairment Symbol.

The Symbol is an expression of the commitment of an organisation to provide a good service to a person with dementia. It signifies that an organisation has provided the necessary staff training to ensure an understanding of dementia and how to communicate with people who have cognitive impairment. It is for the individual to decide whether to access the service.

The symbol lets people living with dementia know that an organisation is dementia friendly and has staff who are specially trained. We believe it could be part of a strategy to promote better care in hospitals as has been the case in Victoria. Similarly, in the community it would work as a way of encouraging commercial and community services to consider how they can better meet the needs of the increasing numbers of people who have cognitive impairment.

There is a low level of understanding of cognitive impairment in Australia. Most people understand that dementia is associated with memory loss, but few understand the other difficulties faced by a person with dementia which can include behavioral symptoms, difficulties with language, comprehension and visual disturbances. We aim to find positive ways to raise awareness of dementia and also to support individuals with dementia to remain active in their community for as long as possible.



Lucille Bloch
Chairperson, National Consumer Advisory Committee
May, 2013

INTRODUCTION

People with dementia and their families face significant stigma and discrimination after a diagnosis of dementia. Often they struggle to access appropriate services and support because there is a lack of understanding about the needs of a person with dementia and how best to communicate with them.

The purpose of this paper is to provide an overview of an approach to promoting dementia friendly organisations through the use of a cognitive impairment symbol in Australia and overseas. This paper identifies the need for such a symbol, and provides recommendations regarding the national implementation of a symbol.

For the purposes of this paper 'cognitive impairment' refers to any individual experiencing deficits in one or more of the areas of memory, perception, attention, verbal ability, and judgment.

There has been substantial debate in Australia about the benefits and risks of using a cognitive impairment symbol. Individuals with dementia and their families have indicated that a symbol, if used appropriately, would be beneficial to people with cognitive impairment and dementia and would promote access to appropriate care and support. Alzheimer's Australia believes it is now time to launch the symbol nationally.

The successful release and application of a cognitive impairment symbol will depend on the following conditions being met:

- 1 Individual choice: The symbol will only be used on an opt-in basis. The decision to be identified as having a cognitive impairment lies solely with the individual and their family carer. If a community service identifies particular staff as being trained to assist people with cognitive impairment, it is up to the individual with cognitive impairment to decide if they want to utilise the specialised service.**
- 2 Nature of the symbol: Consumers and service providers must be educated in how the symbol will be employed. The symbol will be utilised in two ways: 1) as a symbol that a business or particular staff member has undergone training on cognitive impairment 2) as a bedside identifier within an acute care setting.**
- 3 Organisational training: Training and education of staff is essential to ensure the correct use of the symbol. A training package will be developed to be used alongside the symbol which will include information relating to cognitive impairment and dementia, the purpose of the symbol and effective communication strategies.**

WHAT IS A COGNITIVE IMPAIRMENT SYMBOL?

Symbols are used in a variety of settings to communicate information. For instance, the wheelchair symbol is frequently used to indicate accessibility to services or places for people in a wheelchair or the elderly.

The concept of a national symbol for dementia in Australia came about at the National Consumer Summit on Dementia held in 2005. Use of visual and hearing impaired symbols in acute care settings provided the inspiration for the idea. Consumers indicated at the time that people with dementia and their carers 'need to see a national symbol for cognitive impairment so that people with dementia are treated appropriately, particularly in the delivery of service.'

Support for the use of a symbol in both acute care settings and in community settings has steadily grown since the 2005 summit with many stakeholders indicating the symbol could ensure that people living with dementia receive appropriate care, indicate appropriate customer service for people with dementia and their family carers and, more importantly, promote a better awareness of dementia, thus reducing the stigma commonly experienced by people living with dementia and their family carers.¹

In 2003 Ballarat Health Services (BHS) in Victoria, Australia conducted a comprehensive project to introduce a Cognitive Impairment Identifier (CII) symbol, incorporating staff training and education (Figure 1). Consumer consultations undertaken as a part of the project revealed a consumer preference for an abstract symbol that is readily recognisable. The results of the study overlap with findings from the Dementia Symbol Research Project undertaken in 2008 in which consumers highlighted their preference for a small, abstract symbol in an acceptable colour to be released in conjunction with staff education in the various settings.¹



Figure 1 Cognitive impairment identifier – Ballarat Health Services
© Ballarat Health Services.¹

¹ Image used with permission from A/Professor Mark Yates, Ballarat Health Services.

WHO MIGHT BENEFIT FROM THE SYMBOL?

Individuals with cognitive impairment of any type would benefit from the use of the symbol. This could include individuals with cognitive disabilities, acquired brain injury, mild cognitive impairment and dementia. High rates of cognitive impairment in the acute care setting have been reported in numerous studies with 33-60 per cent of older patients receiving hospital care estimated to have some form of cognitive impairment.²

Dementia is the leading cause of disability in Australians aged 65 and over with an estimated 321,000 people living with dementia and nearly 1.2 million people caring for someone living with dementia.³ Despite the high prevalence of dementia in our community, there is still a lack of understanding about the disease and there is significant stigma associated with a diagnosis.¹ A recent study found that of those surveyed, a third of people found individuals with dementia irritating and ten per cent indicated they would actively avoid spending time with people who had a diagnosis of dementia.⁴

Individuals with dementia also face difficulty when seeking services in the community as organisations rarely have staff available that has been trained to communicate appropriately with a person who has cognitive impairment. Due to lack of social supports, individuals with dementia and their carers often become socially isolated.

Individuals with cognitive impairment face considerable challenges in acute care settings, where staff may be unaware of their impairment or not trained in how to work with people who have a cognitive impairment and dementia. A recent report by the Australian Institute for Health and Welfare (AIHW) found that in NSW dementia was not recorded as a diagnosis in almost half of the hospital stays for people with dementia.⁵ Lack of identification and inadequate training for staff can lead to poor outcomes for people with cognitive impairment and increased behavioural and psychological symptoms of dementia.

IS A COGNITIVE IMPAIRMENT SYMBOL ETHICAL?

The need for a distinct cognitive impairment symbol in acute care settings and the broader community has long been debated among care professionals and consumers both within Australia and internationally.

A number of issues have been raised regarding the use of a symbol, including an increase in stigmatisation and vulnerability of people with a cognitive impairment.^{1,6} There are also concerns that the individual may be more susceptible to financial and other forms of abuse if they identify as having cognitive impairment.

Although the issues outlined above warrant consideration, consumers have indicated that the benefits of an opt-in symbol outweigh the risks. The symbol has the potential to raise awareness of cognitive impairment, improve the quality of services available for people living with cognitive impairment and promote social inclusion. Therefore, Alzheimer's Australia and the relevant stakeholders support the use of a symbol and are prepared to address ethical issues that arise with the use of the symbol.

To assist in moderating the risks associated with a cognitive impairment symbol, the use of the symbol should be subject to specific guidelines. This would include the use of the symbol in settings where staff had been appropriately trained to respond to the needs of people living with cognitive impairment and dementia. Training would incorporate general information about cognitive impairment and dementia, the purpose of the symbol, effective communication strategies and addressing problematic behaviours when caring for people with dementia. The release of a symbol will be supported by a national awareness campaign in order to raise the profile of dementia and educate consumers and service providers as to what the symbol represents.

THE NEED FOR A COGNITIVE IMPAIRMENT SYMBOL IN AUSTRALIA

Consumer perspective

The idea of a cognitive impairment symbol in Australia was first raised by consumers at the 2005 Alzheimer's Australia National Consumer Summit. One of the outcomes of the Summit was a seven point action plan for change. It included the recommendation that, "people with dementia and carers need to see a national symbol for cognitive impairment so that people with dementia are treated appropriately, particularly in the delivery of service". The consumers envisaged that the symbol could be used both to identify 'dementia friendly' services or staff, and also to identify a person who has a cognitive impairment as requiring additional support.

In 2008, Alzheimer's Australia undertook the Dementia Research Project – *Getting Dementia out of the Closet* in consultation with personnel from Catholic Health Australia (CHA) and the Queensland University of Technology (QUT) to assess the viability and possible impact of a national symbol in a range of settings. As part of the project, focus groups were established to discuss the introduction of a national symbol. The focus groups included individuals from a variety of backgrounds, including acute care, community, residential, transitional, emergency services and the broader community.¹ In addition, more than 160 consumers responded to surveys about the symbol.

The key findings from the surveys and focus groups showed that people living with dementia, family carers, care workers and service providers strongly supported the use of a symbol in acute care settings. It was believed that the use of the symbol would assist in informing clinical and non-clinical staff of the client's condition and so aid staff in tailoring their care services, communication and behaviour to the needs of the person living with dementia. Consumers reported that this in turn could help to lower the anxiety experienced by both people living with dementia and their family carers about the quality of care being provided. Healthcare workers and service providers also stated that one of the main benefits of a symbol would be staff education about dementia care.¹

People living with dementia and their family carers also supported the use of a symbol in other settings, including transitional care, emergency services and residential care. Consumers thought that the use of a symbol may improve response times of emergency workers, assist workers to make decisions about the most appropriate course of action, encourage the implementation of staff training as

well as promote quality dementia care practice. Nearly three-quarters of respondents also felt that advertising, education and information campaigns should coincide with the introduction of a symbol.¹ As a result of the study, recommendations were made for the implementation of a symbol nationally (*See Appendix 1*).

Research undertaken at the Ballarat Health Services in 2003 into the use of a bedside CII revealed overwhelming consumer support for the use of a CII. Of 39 participants, 37 were interviewed and indicated 'yes' to the use of an alert; 32 of the respondents indicated their preference for the use of a bedside identifier whilst an alert attached to the patient was rejected. The majority of participants suggested the use of an abstract symbol that would be readily recognised and subtle in colouring.⁷

Health profession perspective

Education and Training of Staff in Dementia Care and Management in Acute Settings Project

A trial of a bedside CII was undertaken at the Ballarat Health Services in 2003 and the evaluation was largely positive. The CII was paired with 40-minute staff training sessions comprising PowerPoint presentations and the video *Carers experience of the acute hospital system*, which aimed to improve awareness of and communication with people with dementia.⁸ Staff completed pre and post training surveys: significant increases in staff knowledge, confidence, comfort and job satisfaction in dealing with patients with dementia was reported. Nearly 56 per cent of the 122 staff surveyed reported that the presence of a CII affected the way they communicated with patients with dementia (for example, paid more attention to communication and utilised better principles of communication) and 23 per cent reported a change in interaction with carers. Surveys of family carers reported that, on average, care had improved across all domains by 11 per cent.⁸

The CII remains in use at the Ballarat Health Services and has been implemented at other health services in Victoria. In addition to improving staff knowledge and confidence, the symbol also led to better identification of people with dementia, delirium, or memory and thinking problems in hospital.⁸ Since 2007, the CII has been implemented in 22 health services in Victoria, with these organisations working in partnership with Ballarat Health Services and undergoing extensive hospital-wide education on the use of the CII and the philosophy of care attached to the symbol.

HOW HAVE COGNITIVE IMPAIRMENT SYMBOLS BEEN USED INTERNATIONALLY?

Acute care

The Butterfly Scheme – United Kingdom

The Butterfly Scheme, developed by a family carer of a person with dementia, was launched in the United Kingdom and has now been implemented in nearly 50 hospitals across England, Scotland and Wales. The project uses a bedside visual identifier which is accompanied by education for clinical and non-clinical staff. Butterfly Scheme champions are chosen on each ward and in each team around the hospital (e.g. nurses, therapists) to promote appropriate care. These champions also ensure temporary or new staff are introduced to the scheme. The scheme incorporates 1.5-hour workshop sessions for Butterfly Scheme champions plus a series of 40-minute drop-in presentations at various times to enable as many staff as possible to attend sessions.

The scheme also uses a carer document, which allows carers to share their expertise in the patient's care. This document is stored where it can be accessed by all staff caring for the patient, and the butterfly symbol alerts staff to the existence of such a sheet. Simple pointers, such as how to address the patient, how they take their tea/coffee, can help to reduce stress levels and increase patient wellbeing. The carer document has been highlighted as particularly beneficial, given the high number of staff that have contact with each patient. The scheme is opt-in for people living with dementia and their carers, with opt-in rates running close to 100 per cent. The Butterfly Scheme is currently under review with an evaluation report expected in early 2013.

Broader community

A number of projects are being undertaken internationally in the use of a symbol in the broader community. For example, in Bruges a symbol – a knotted handkerchief – is displayed in windows of local businesses to indicate to those with cognitive impairment and dementia that they will receive an empathic reception. The symbol also serves as a reminder for staff of their dementia-awareness training.⁹ The Bruges project was awarded The European Foundations' Initiative on Dementia (EFID) award in early 2012 for the program's success in fighting the stigma associated with dementia and engaging the whole community in being respectful and tolerant of people living with dementia.

Similar dementia-friendly projects are being launched in more than 20 locations across England, all of whom have committed to working towards becoming dementia-friendly villages, towns and cities. The process and criteria for what constitutes a dementia-friendly community is still under development.

A forget-me-not symbol will be employed to recognise dementia-friendly communities, companies and organisations. The projects detailed above have yet to be formally evaluated. For further information, visit <http://dementiachallenge.dh.gov.uk/2012/11/08dfcachievements/>

THE WAY AHEAD FOR THE IMPLEMENTATION OF A COGNITIVE IMPAIRMENT SYMBOL IN AUSTRALIA

Alzheimer's Australia believes that national implementation of the symbol would lead to significant benefits for people with dementia and their families. It would identify organisations that had made a commitment to meeting the needs of individuals with cognitive impairment. The use of a symbol in these settings will allow people living with dementia and their carers to readily access services and will increase the level of customer service received. In the community, the symbol would enable people with dementia to access dementia-friendly services and would promote social inclusion. The implementation of the symbol in a given setting will be subject to the following conditions.

Acute care

The implementation of a national symbol in Australian hospitals must be conditional on:

- people with cognitive impairment having the right to choose whether they wish to be identified
- staff training and education on dementia care and communication
- executive-level support as implementation of a symbol will necessitate a review of hospital procedures and policies to ensure the quality of dementia management practices
- funding for training and implementation
- champions – a select number of staff members who will ensure that the symbol is applied appropriately and provide further information about the symbol when necessary.

Broader community

In the community, the use of the symbol would require an ongoing commitment by the organisation to work towards being dementia friendly. There are countless opportunities for a symbol to be employed in community settings including banks, post offices, public transport and other services, including Centrelink. The use of a symbol in these settings will allow people living with dementia and their carers to readily access services and will increase the level of customer service received.

The use of a symbol in the broader community would be conditional on:

- adoption of specific guidelines for the use of the symbol
- staff undertaking training and education on communicating with individuals who have cognitive impairment.

WHAT OPPORTUNITIES ARE THERE FOR NATIONAL IMPLEMENTATION OF THE SYMBOL?

Acute care

In 2012, the Australian Government released the *Living Longer. Living Better.* aged care reform package. As a part of the package, \$39.2 million will be provided over five years to improve hospital services for people with dementia. The funding will go toward the development and dissemination of nationally agreed principles and protocols for the management of people with dementia in acute care settings. In particular, early identification of people with cognitive impairment, improved assessment and access to specialist dementia programs, and the development and coordination of support systems will form the basis of hospital reforms. The development and dissemination of nationally agreed principles and protocols for the management of people living with dementia in acute care provides a timely opportunity for the release of a cognitive impairment symbol.

Community

Although the implementation of a cognitive impairment symbol in the broader community is complex, it has been largely supported by service providers: 'If we know that someone has dementia we are able to tailor the information we give them to their needs, that is, not giving too much information, giving written information, or involving the carer in providing information.'¹ The use of the symbol may therefore improve communication between people who have cognitive impairment and dementia and other community members, and give the person with cognitive impairment the confidence to access services.¹

Partnerships and collaborations will need to be established with local organisations in order to ascertain their educational needs and develop resources to assist staff in their response to people living with cognitive impairment and dementia. Consumers commonly cite local facilities including public transport, banks, shops and libraries as particularly important as these facilities are recurrently used and provide the person living with dementia a 'connection' to their community.

In order to engage organisations, it may be necessary to provide a discussion on the costs and benefits of promoting a dementia-friendly approach. There is a need for a national education resource that can be made available to businesses who are interested in pursuing this approach. Champions could play an important role in engaging community organisations and raising awareness of the symbol and its purpose.

For further information about the implementation of a symbol nationally, refer to *Appendix 1*.

RECOMMENDATIONS FOR THE IMPLEMENTATION OF A COGNITIVE IMPAIRMENT SYMBOL

Alzheimer's Australia recommends that the following approach should be adopted to get action on the use of a symbol.

Recommendation 1

The national symbol should be implemented, because its introduction has been strongly supported by people with dementia and their carers, by other stakeholders, including services and professionals, and by the evaluation of the Cognitive Impairment Identifier (CII) in Ballarat.

Recommendation 2

The symbol should represent cognitive impairment generally rather than dementia alone. In order to facilitate assistance to the broadest range of consumers, the symbol should be available in a range of physical formats to accommodate personal preference and use in various settings; for example, signage in care settings, a bedside identifier or posters within acute care settings providing information about the symbol.

Recommendation 3

In all instances, the use of a symbol should be voluntary.

Recommendation 4

An education and training package as well as specific guidelines for use of the symbol should be developed.

Recommendation 5

The symbol should be progressively introduced starting with acute care, Centrelink and banks.

Recommendation 6

The implementation process should be driven nationally by the Australian Government, through the Council of Australian Governments (COAG) within the context of the *National Framework for Action on Dementia*, in consultation with key stakeholders. Implementation of the symbol, in the domains specified, would involve:

- physical formats of the symbol to accommodate personal preferences and use in various settings
- protocols for use, accompanied by clear parameters, philosophy, sensitivity to needs of culturally and linguistically diverse (CALD) and Aboriginal and Torres Strait Islander (ATSI) populations, and consent guidelines
- an education and training program on cognitive impairment
- evaluation and quality-assurance processes, embedded where possible into existing quality-assurance, accreditation or reporting systems.

Recommendation 7

International adoption of the symbol should be pursued through relevant international bodies such as the World Health Organization, Alzheimer Europe, Alzheimer's Disease International and the International Psychogeriatric Association.

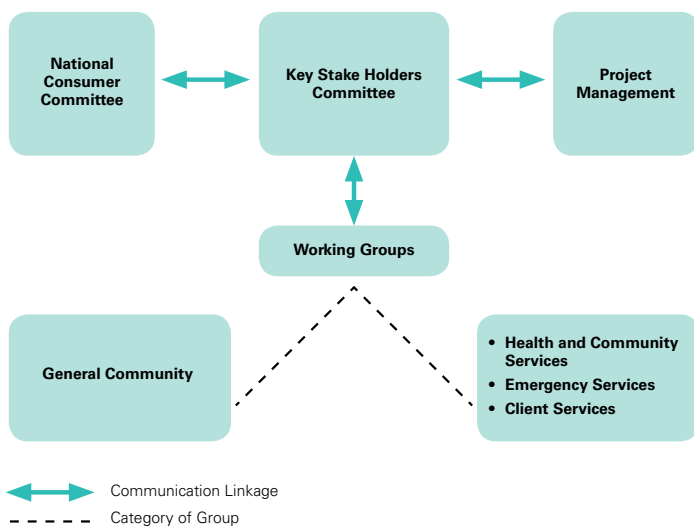
APPENDIX I

(Dementia Symbol Research Project: *Getting Dementia out of the Closet*, 2008).

Steps to Implement the Cognitive Impairment Symbol

Flow chart of implementation structure

Steps to implement the symbol nationally



Establishment stage

- Project management to establish three key groups that will be responsible for the development and implementation of a symbol. These groups are:
 - Key Stakeholder Committee, which includes representation from all the working groups, community groups and other stakeholders
 - working groups, including health and community services, emergency services and client services
- Identify and allocate budgetary and other resources
- Ensure ongoing consumer input and advice by establishing a communication protocol between the National Consumer Advisory Committee (NCAC) of Alzheimer's Australia and the Key Stakeholder Committee
- Establish evaluation measures

Symbol identifier stage

The symbol identifier stage includes consideration of how to adopt the Ballarat Health Services cognitive impairment identifier (CII) as the national symbol and developing accompanying education and training strategies and resources.

- The Key Stakeholder Committee is to identify issues to be addressed in adoption of the Ballarat Health Services CII, such as:
 - contractual and copyright issues relating to use of the Ballarat Health Services CII
 - the physical formats that should be used
 - meeting the needs of special groups, for example, people from a CALD background.
- Although already existing symbols include the Ballarat Health Services CII, Ballina Regional Hospital Pelican identifier, Safe Return program in the United States of America identifier, Alzheimer's Foundation of America and MedicAlert® bracelet, North Coast Area Health Service delirium risk identifier, and Western Australia Country Health Service forget-me-not flower Identifier, the use of the Ballarat Health Services CII is supported because it has been developed through a consumer consultative process and had been widely tested, with subsequent positive evaluation.⁷

The symbol should be implemented nationally in accordance with the recommendations. There is clear support for the symbol to be introduced without any piloting.

During the implementation process, particular attention should be given to the needs of culturally and linguistically diverse (CALD) groups and Aboriginal and Torres Strait Islander (ATSI) groups.

Implementation should be undertaken in stages, as follows:

- Particular needs to be addressed include:
 - colour blindness
 - ATSI perspectives
 - CALD perspectives.
- All working groups are to develop appropriate protocols for use of the symbol in their own sectors and for systemic adoption.
- A system to evaluate and monitor continuous improvement in the implementation of the symbol in each care setting needs to be established. This might involve developing surveys to gauge the success of the implementation of the symbol. Similar to research completed at Ballarat Health Services and Ballina Regional Hospital, this evaluation would compare the attitudes, behaviours and understanding of all involved both before and after implementation.
- Development of education and training strategies
- Education and training strategies for each domain need to be established, to deliver programs to support the implementation of the symbol.
 - Where possible, existing education and training courses and programs should be reviewed to ensure that they have symbol-specific information.
 - Induction programs for staff in all appropriate settings might also include providing information about the symbol.
 - Staff development and continuous professional development programs should also be reviewed for symbol content.

Communication strategy

In accordance with the symbol project recommendations for the dementia communication strategy, an extensive

information and advertising campaign will be required to ensure understanding and knowledge of the symbol by the public. This might include:

- television advertisements, which might fit within the community service obligations of commercial stations
- radio advertisements
- newspaper advertisements
- letter box information pamphlets
- posters for public areas.

Implementation stage

This will involve implementation of the symbol in domains agreed by the Project Steering Committee. Initially these would include:

- health and community services, with acute care as a priority
- emergency services, including ambulance, fire, and police
- client services such as banking and government services.

In particular settings, this might involve:

- development of a consent process and patient/carer information pack
- development of protective privacy and legal protocols
- development of appropriate policies and procedures.

Additional tasks include:

- monitoring the progress of the implementation and analysing the outcomes
- development of quality assurance and evaluation procedures.

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These documents and others available on www.fightdementia.org.au

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WWW.FIGHTDEMENTIA.ORG.AU

for comprehensive information about
dementia and care
information, education and training
other services offered by
member organisations

Or for information and advice contact the
National Dementia Helpline on

1800 100 500

(National Dementia Helpline is a
Australian Government funded initiative)

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