Dementia in Primary Care
A Guide for Healthcare Professionals Working in Dementia Care
This booklet has been developed by Joanne Flood, Community Education and Development Officer with Home Instead Senior Care in Belfield. Joanne is a Registered Psychiatric Nurse with 10 years experience in dementia care in Acute Care Settings, Liaison Psychiatry, Gerontological Nursing, Long Term Care Settings and more recently working in the community as a Dementia Nurse Specialist with Psychiatry of Old Age in North County Dublin. Joanne has completed a PGDip in Gerontological Nursing and MSc in Mental Health of Older People. Joanne is currently undertaking a PhD in Community Dementia Care in Dublin City University.

Joanne Flood, RPN, PGDip, MSc
Acknowledgements

Home Instead Senior Care would like to express its gratitude to Dr Suzanne Cahill, Dr Mary Cosgrave, Dr Kate Irving, Dr Navroop Johnson, Dr Declan Lyons and Jackie O’Toole for their contribution to this booklet. This booklet could not have been put together without their expert knowledge.

About the contributors:

Dr. Suzanne Cahill is Director of The Dementia Services Information and Development Centre's research programme at Trinity College Dublin. She is also an Adjunct Associate Professor of Social Work and Social Policy at the University of Queensland, Australia.

Dr. Mary Cosgrave is a Consultant in Old Age Psychiatry in St Ita’s Hospital, Beaumont Hospital and Community Care Area 8 since March 2002. She is an Honorary Senior Lecturer in Psychiatry at the Royal College of Surgeons in Ireland and has been Executive Clinical Director of the North Dublin Mental Health Services since June 2009.

Dr. Kate Irving is a Lecturer in Nursing at Dublin City University. She has a PhD from Curtin University, Western Australia and has a special interest in the care of people with dementia particularly in the early stage. Dr. Irving runs a self referral service for people who feel they have memory problems, the service is located in The Healthy Living Centre, Dublin City University.

Dr. Navroop Johnson is a medical graduate of the Ludhiana Christian Medical College in Punjab, India and has recently completed postgraduate examinations in Psychiatry. He has worked in St Patrick's Hospital as part of the Dublin City University rotation. He has research interests in medical informatics and medical management.

Dr. Declan Lyons is a Consultant in Old Age and General Adult Psychiatry who works at St Patrick’s Hospital. He is a graduate of Trinity College Dublin and King’s College London and has research interests in ethical and human rights issues as applied to healthcare, social psychology, medical teaching and memory disorders.

Jackie O’Toole is a Registered Psychiatric Nurse with a Post Graduate Diploma in Mental Health of the Older Person. Jackie is Senior Lead Tutor in Sonas aPc, Chairperson of the Irish Association of Activity Nurses and Carers and the founder of Dementia Training Ireland.
Table of Contents:

1: Introduction 4

2: Philosophy of Dementia Care 5

3: What is Dementia? 6

   3.1: Dementia in the Irish Context 6

4: Types of Dementia 7

5: Early Signs of Dementia 8

6: Differentiating Delirium and Dementia 9

   6.1: Screening for Delirium 10

   6.2: Screening for Dementia 10

7: Challenging Behaviour/BPSD 11

   7.1: Understanding Aggression and Agitation 12

   7.2: Understanding Wandering 13

8: Assessment of the Individual Suffering from BPSD 14

9: Assessment of Carer and Family Members 15

10: Capacity Assessment in Dementia Care 16

11: General Approaches and Strategies in Dementia Care 17

12: Achieving Person-Centred Communication 19

13: Top Tips in Dementia Care 20

14: Do’s and Don’ts of Communication 21

15: Palliative Care in Dementia 22

Appendices 23
1 - Introduction

There are currently more than 40,000 people in Ireland with some form of dementia. Most of the people who suffer from dementia are aged over 65, the sector of the population which is increasing most rapidly. Unless there is a medical breakthrough, by 2036 the number of people with dementia in Ireland is expected to increase by more than 300 per cent.

That's why Home Instead Senior Care, Ireland's trusted source of home care for seniors, has produced this booklet- to provide a resource for healthcare practitioners caring for the increasing number of dementia patients. The booklet also features contributions from Ireland's most esteemed dementia experts, addressing central issues about dementia care such as general approaches to dementia care, capacity assessment of a person suffering from dementia and distinguishing dementia and delirium.

As Ireland's trusted source of home care for seniors, Home Instead Senior Care has a vested interest in senior care issues such as dementia and we hope anyone involved in gerontology, psychiatry, and general medicine will find the booklet to be a practical guide.
2 - Philosophy of Dementia Care

Medical practitioners have differing perspectives regarding dementia and dementia sufferers. What a practitioner thinks and feels about dementia greatly influences their approach to care and how they interact with those suffering from the condition.

It is therefore important for those working with dementia patients to reflect on their approach to care. A person-centred approach is recommended to ensure the patient receives personalised and sensitive care which enables the dementia sufferer and their family members who care for them to feel they have an active role in the treatment process.

It is therefore important to consult and listen to dementia patients and their family members during every step of the treatment process. These people are not passive victims of the disease and have the right to play an active role in coping with dementia. Adopting a person-centred approach offers medical professionals the opportunity to improve peoples experience of the illness and will help dementia sufferers live a more fulfilling life.
3 - What is Dementia?

The World Health Organisation describes dementia as:

“...a syndrome due to disease of the brain, usually of a chronic or progressive nature, of which there is impairment of multiple higher cortical functions...”.

Such functions include:

- memory
- forgetfulness of recent events
- comprehension
- calculation
- language
- learning capacity
- judgement

3.1 - Dementia in the Irish Context

- There are approximately more than 40,000 dementia sufferers in Ireland.
- 11 new cases of dementia are diagnosed on a daily basis and continuation of this trend will result in 71,000 active cases by the year 2026.
- 36 - 53% of dementia sufferers in Ireland experience a mild-moderate degree of the condition.
- 35% of dementia sufferers have high dependence levels.
- 76% of the overall care of all dementia sufferers is taken up by family members.

Sources of information: Irish Alzheimer Society, National Council on Ageing and Older People and Parsons 2001
4 - Types of Dementia

1 - Alzheimer's Disease - Accounts for 50 - 70% of dementias

Alzheimer's disease is the most common form of dementia. It is an incurable, degenerative disease. Early symptoms of the disease include memory loss, such as forgetfulness of recent events. However, people with Alzheimer's continue to recall distant events. As the disease progresses, symptoms include confusion, mood swings, and long-term memory loss.

2 - Vascular Dementia - Accounts for 20 - 30% of dementias

Vascular dementia is the second most common form of dementia. Those with history of stroke and transient ischemic attack suffer a high risk of developing vascular dementia. It results in memory loss, problems with concentration and comprehension. Disturbance in abstract thinking, judgement, impulse control and personality may also develop.

3 - Dementia Lewy Body - Accounts for 15 - 25% of dementias

People with Lewy body dementia suffer an impairment in their perception, thinking and behaviour. They also experience visual hallucinations, fluctuating memory and Parkinson's-like symptoms such as tremors. People with lewy body dementia also suffer an increased risk of falls as a result of the Parkinsons-like symptoms.

4 - Fronto-Temporal Dementia - Accounts for approximately 10% of all dementias

Fronto-temporal dementia is caused by the degeneration of the frontal lobe of the brain and may extend back to the temporal lobe. In the early stages of the disease, memory can stay intact but personality and behaviour change as people lose their inhibitions, act rudely or become easily impatient. People with fronto-temporal dementia are not aware of their actions and as the dementia progresses, memory loss and the ability to perform activities of daily living decline.

Source: Alzheimer Europe 2009
5 - Early Signs of Dementia

The early signs of dementia are quite subtle and may not be immediately obvious. Typically people first seem to notice that there is a problem with memory, particularly in remembering recent events. Other early signs and symptoms of dementia include:

- Difficulty performing everyday tasks
- Forgetfulness of recent events
- Misplacing things or mixing up appointments, bills or prescriptions

People have the right to know if they are suffering from dementia and if diagnosed early the person will more likely be able to understand the implications of the disease and may be involved in planning for the future.

Early detection and diagnosis are the first steps in designing a dementia management strategy. It also helps treat other ailments which may accompany the early stage of dementia, such as depression and anxiety.


Home Instead Senior Care similarly believes that home care prolongs entry to a nursing home and also improves the quality of life of both the older person and their families. By providing home care, Home Instead Senior Care alleviates the burden of care experienced by many families taking care of elderly loved ones, particularly those suffering from dementia.
6 - Differentiating Delirium and Dementia

Delirium is a sudden, fluctuating, and usually reversible disturbance of mental function. It is a temporary condition and if the cause is identified and treated quickly, it can usually be cured.

The Diagnostic and Statistical Manual of Mental Disorders (DSM IV) criteria for a diagnosis of delirium include:

- Disturbance of consciousness such as reduced clarity of awareness of the environment and reduced ability to pay attention.
- A change in cognition such as disorientation that is not due to a case of pre-existing, established or evolving dementia.
- The disturbance develops over a short period of time (usually hours to days) and tends to fluctuate during the course of the day.
- There is evidence from the history, physical examination or laboratory findings that the disturbance is caused by the direct physiological consequences of a general medical condition or drug use.

These criteria help to differentiate delirium from dementia or help identify delirium superimposed on a pre-existing dementia. Delirium superimposed on dementia is often very difficult to identify and can be left untreated as both conditions cause confusion. To distinguish between the two, physicians need to pay particular attention to the onset and duration, and what the person's baseline or previous level of confusion or cognitive impairment was. Lastly, it is also important to treat any serious worsening of confusion in a person with dementia as delirium until proven otherwise.

For further information on delirium please visit:
6.1 - Screening for Delirium

The routine investigations for delirium include:

- **Full delirium screen** to rule out any infective or medical cause with a view to treating. This includes: full blood count; liver profile; renal profile; bone profile; erythrocyte sedimentation rate; vitamin B12; serum folate; thyroid function tests; calcium; glucose; urinalysis; sputum sample or chest x-ray; and toxicology screen.

- The **Confusion Assessment Method (CAM)** is a comprehensive assessment instrument that screens for features of delirium and correlates to DSM IV criteria.

6.2 - Screening for Dementia

The routine investigations for dementia include:

- **Clinical assessment** including history taking, physical examination and other appropriate examinations.

- The **mini-mental state examination** or Folstein test. A score of 25 - 30 points is normal, below this scores can indicate severe (≤9 points), moderate (10-20 points) or mild (21-24 points) cognitive impairment.

- A **medication review** will identify drugs that may adversely affect cognitive functioning.

- **Laboratory testing** will rule out treatable causes. These tests include: full blood count; liver profile; renal profile; bone profile; erythrocyte sedimentation rate; vitamin B12; serum folate; thyroid; calcium and glucose.
7 - Challenging Behaviour/BPSD

When a person has dementia, one or more area of the brain is damaged. The damaged areas are different for each person and the individual cannot control their behaviour resulting from this brain damage. According to the International Psychogeriatric Association (IPA), Behavioural and Psychological Symptoms of Dementia (BPSD) will occur in 70% - 90% of people with the condition. These symptoms include:

**Behavioural:**
- restlessness
- physical aggression
- screaming
- agitation
- wandering
- culturally inappropriate behaviours such as sexual disinhibition, hoarding, cursing and shadowing

**Psychological:**
- anxiety
- depressed mood
- hallucinations and delusions

Further information on these symptoms is available from the International Psychogeriatric Association website: www.ipa-online.org.
7.1 - Understanding Aggression and Agitation

According to Cohen-Mansfield and Billig 1986, people with dementia may behave aggressively or agitated in one or more of the following ways:

- **Physically aggressive behaviour** such as hitting; kicking; pushing; spitting; biting; scratching; grabbing or clinging onto people; hurting themselves or others; or throwing things.

- **Verbally aggressive behaviour** such as shouting or cursing at others.

- **Physically non-aggressive behaviour** such as pacing; restlessness; wandering; repetitive mannerisms; inappropriate disrobing or undressing; hoarding or hiding.

- **Verbally agitated behaviour** such as repeated requests for attention, strange noises and negativism.

By understanding what may cause such behaviour, medical professionals and caregivers can take steps to ensure such behaviour happens less often. According to Katz 2000, only 2% of aggressive events have been found to occur without an antecedent so it makes sense to make an effort to understand what makes a person with dementia behave in an aggressive manner.

For example, **invading an individual’s personal space** will result in defensive or resistive behaviour. Exposing a confused person to the upsetting reality that they are unwell can also distress them or explaining that a loved one has passed away will just upset the person and make them relive the painful memory.

An **abrupt or sudden approach** to a person with dementia or unexpected physical contact may result in the person being physically alarmed. Attempting to restrict or control the wishes and choices of the person may provoke an aggressive response.

In some cases aggression may be linked to **delusions**, for instance they may be convinced that the neighbours are trying to kill them or poison them. It is therefore important to understand what might be the meaning behind the aggressive behaviour or agitation the patient is exhibiting. This will help medical professionals and carers from doing anything that may trigger aggression or agitation in the dementia patient.
7.2 - Understanding Wandering

Those suffering from dementia are prone to wandering and do so for many different reasons, such as:

- **Exit seeking** – They repeatedly attempt to leave the house or a room or if they are living in a nursing home they may attempt to abscond.

- **Self stimulation** – Such patients are bored or under stimulated and may pace or wander around the house particularly late in the evening.

- **Modellers** – They may shadow or follow family members around the house.

- **Restlessness** – Some people suffer from akathisia as a result of certain medications. This condition is characterised by sensations of restlessness that manifests itself with an inability to remain still.

- **Sundowning** - According to the Dementia Management Strategy Australia 2006, some people with dementia demonstrate increased restlessness, agitation, anxiety and confusion, especially after dusk. Sundowning behaviours are usually the result of end-of-day tiredness; disturbance in the biological clock; restlessness due to boredom; and decreased need for sleep.

A **rummage box** is useful when trying to redirect a dementia patient from wandering or sundowning behaviours. Leave the box for the person with dementia by an exit door to distract them. The box should be filled with nostalgic objects that will help the person connect with their past as they retain their long-term memories. For example, including old photographs in the rummage box will help people **REMINISCE**.

Section 11: General Approaches and Strategies in Dementia Care will also help you cope with a person with dementia exhibiting sundowning and wandering behaviours.
8 - Assessment of the Individual Suffering from BPSD

The IPA advises healthcare professionals to follow the steps below when assessing the person exhibiting BPSD:

- Characterise the behaviour precisely with special attention to the circumstances under which it occurs. Was it gradual or sudden? Sudden changes in cognition or behaviour may be the result of delirium and must be ruled out before diagnosing dementia.

- Consider if the person's behaviour is the result of an underlying goal or if they are misperceiving their environment or the situation. For example, they might feel they must go collect the children from school at a certain time each day when the children are now adults.

- Review medications and become aware of all side effects and possible drug interactions.

- Be vigilant of any progression in the condition and potential change in symptoms. Mood disorders such as depression and anxiety may occur in the milder stages of dementia and challenging behaviour may occur in the moderate stages of the condition.

- Examine the patient with attention to changes in mental status from baseline. Look for signs of painful and/or uncomfortable physical conditions. Pain can be a factor in challenging or resistive behaviour particularly when being moved or changed.

It is also important to review the patients psychiatric history, social history and premorbid personality. If they were always active people they may need to be kept busy and active. If they were solitary and unsociable they may require a very low stimulus environment.
9 - Assessment of Carer and Family Members

It is also important to assess the family members caring for the person with dementia in relation to their understanding of BPSD and their coping abilities. Adams 2008 suggests healthcare professionals take the following steps when assessing those caring for a person with BPSD:

- **Step 1: Identify the problem** – Help carers better understand the problem.
- **Step 2: List all possible solutions** – Encourage the carer to list different ways in which the problem may be solved.
- **Step 3: Highlight the strengths and advantages** – Encourage the carer to list the advantages and disadvantages of each solution.
- **Step 4: Choose the best solution** – Assess the strengths and weaknesses of each solution and help the carer identify the best solution.
- **Step 5: Implement the solution** – Help carers plan how to put the suggested solution into action and consider potential problems that may occur.
- **Step 6: Review progress** – Help carers review the effectiveness of the proposed solution.

By completing these steps the healthcare practitioner is helping the carer to increase their understanding of BPSD and how to better cope with the situation. It is also advisable for carers to keep a diary of the experience caring for the person with BPSD. It will help strengthen their insight of the situation and enhance their understanding of the patient and his or her symptoms.
10 - Capacity Assessment in Dementia Care

One of the fundamental freedoms people take for granted is the freedom to make decisions for themselves, even if the decision is seen by others as flawed or irrational. Promoting choice, autonomy and personal responsibility has become a key objective of healthcare systems. Healthcare professionals have a responsibility to ensure the protection of those who are incapable of deciding matters for themselves. A thorough and careful assessment of whether individuals have, or lack, capacity is essential to the protection of a person's rights.

Capacity is specific to a particular decision in hand and someone may be able to consent to some things but not others. In general capacity is assumed to be present unless it is clearly demonstrated to be lacking. Consent means agreement and must be sought at every clinical encounter (involving examination, investigation and treatment) with a competent adult patient.

When a diagnosis of dementia arises with inevitable and progressive intellectual deterioration being apparent, capacity may come repeatedly into question during the different stages of the illness and thus it must be constantly assessed. To be capable a person should be able to:

- understand the decision
- understand the alternative courses of action
- assess which courses of action would be reasonable
- retain memory of decisions and the reasons for them
- communicate their intent

In the event where a patient suffers from a deteriorating or fluctuating mental disorder such as dementia, it is advisable to appoint a power of attorney as early as possible in the illness before the capacity to do so is lost. This involves the patient and the attorney signing a legal document with a witness present and a medical certificate stating the person has sufficient mental capacity to undertake and understand the process. Medical professionals are frequently called upon to report on capacity of an individual so it is important to adopt an objective, meticulous approach to assessment.
11 - General Approaches and Strategies in Dementia Care

It can sometimes be very difficult to get a person with dementia to follow instructions or redirect them away from problematic behaviour.

There is no simple solution and some time and effort is needed in these cases as the wrong approach WILL result in increased agitation or even an aggressive response from the dementia patients.

If you wish to direct or redirect a person with dementia consider the following steps:

1 **Validate:** Validate the emotional state of the person with dementia.

   For example, you could say:
   
   
   "You look worried/upset/annoyed/frightened".

   **Or you could say:**
   
   "You seem to be in good form today".

2 **Align:** Try to align your behaviour with the person's behaviour as much and as safe as possible. For example, you could say:

   "You're looking for someone/something? I lost something too, let's look together”

If the person still feels very focused on a task such as looking for someone or something, encourage them to reminisce about where it is they want to go or who they are looking for. For example, you could say:

"You're trying to get home? What's your home like? Tell me about your home".

   **Or you could say:**
   
   "You're looking for your mother? Tell me about her”.

This helps develop a rapport with the dementia sufferer and aides the person with dementia to reminisce.

However, it is important not to remind him or her that a loved one has passed away or that they no longer live in their childhood home. Here is an example of what NOT to say:

"You want to go home, but this is your home now, you must miss your other home".
Or:

"Are you looking for your mother? You must miss her now that she is no longer here?"

3 Establish a Common Goal or Interest: Once a common goal or interest is established, such as looking for something together, it will be much easier to distract the person from their task. For example, you could say:

"I'm getting tired now, how about you? Will we have a cuppa?"

4 Redirection: Now that the person has been distracted from their original task without becoming distressed it is easier to redirect the person to another task. To do this you could say something like:

"Come to the kitchen and give me a hand making the tea".

Or:

"Sit down on the couch and I'll turn on the TV so we can watch a programme together".

REMEMBER: VALIDATE TO EMPOWER AND REMINISCE TO DISTRACT
This technique can take a little while to master, and you may have to go over the align step a number of times to help make the person with dementia feel listened to and more in control of the situation.
12 - Achieving Person-Centred Communication

The erosion of verbal skills and difficulties with processing language constitute major challenges in dementia care. However, the majority of communication is non-verbal. Behaviour in all human beings is a form of communication and is usually expressing a need or feelings. Once regarded in this way, behaviour becomes a source of understanding rather than conflict.

Dementia is a disability that can be compensated for by positive approaches. The type of dementia and where the person is on their journey of experiencing the disability will determine how communication is impaired at any one time. It is important to establish the person’s reality and to believe there is sense within the conversation.

A person with dementia continues to function at an emotional level and will pick up on another person’s feelings via body language, tone of voice and facial expressions. The use of negative language (words such as "shouldn’t", "can’t", "don’t") may make a person with dementia feel that they are being dismissed and treated like a child. On the other hand, positive language will make a person feel valued and important.

Healthcare practitioners and carers must be aware of how they themselves communicate and learn new ways of communicating to make it easier for people with dementia to understand. It is valuable to know as much about the person as possible and involve family members in drawing their life story. A focus on the person’s communication strengths and retained abilities will also significantly help (they may remember their siblings’ names but not those of their children). Communication deficits should not be taken personally; the person may not remember your name but will definitely remember your kindness.
13 - Top Tips in Dementia Care

STOP: Think about what you are about to do and consider the best way to do it.

PLAN AND EXPLAIN: Who you are; What you want to do; Why you want to do it etc.

SMILE: The person who takes their cue from you will mirror your relaxed and positive body language and tone of voice.

GO SLOW: You have a lot to do and you are in a hurry but the person you are caring for isn’t. How would you feel if someone came into your bedroom, pulled back your blankets and started pulling you out of bed without even giving you time to wake up properly?

GO AWAY: If the person is resistive or aggressive but is NOT causing harm to themselves or others, leave them alone. Give them time to settle down and approach them later.

GIVE THEM SPACE: Avoid any activity that involves invasion of personal space.

BE KIND: The person may not know who you are, but they will know if you are treating them kindly.

STAND ASIDE: Always provide care from the side not the front of the person, where you may be a target to hit, kick etc.

DISTRACT THEM: Talk to the person about things they enjoyed in the past. Whilst you are providing care, allow the person to hold a towel or something that will distract them.

KEEP IT QUIET: Check noise level and reduce it when and where possible. Turn off the radio and TV etc.

DON’T ARGUE: They are RIGHT and you are WRONG! The demented brain tells the person they can’t be wrong.

KNOW THE PERSON: Orientate to their surroundings as necessary. If they become upset by this reality, validate and agree with their feelings, instead of continuing to cause them any more upset.

Adapted from the regional Dementia Management Strategy (Australia 2001)
### 14 - Do’s and Don’ts of Communication

**DO**

- Talk to the person in a tone of voice that conveys respect and dignity.
- Keep your explanations short. Use clear and flexible language.
- Maintain eye contact by positioning yourself at the person’s eye level.
- Look directly at the person and ensure that you have their attention before you speak. Always begin by identifying yourself and explain what it is you propose to do.
- Use visual cues whenever possible. Be realistic in expectations.
- Observe and attempt to interpret the person’s non-verbal communication.
- Paraphrase and use a calm and reassuring tone of voice.
- Speak slowly and say individual words clearly. Use strategies to reduce the effects of hearing impairment.
- Encourage talk about things that they are familiar with.
- Use touch if appropriate.

**DON’T**

- Talk to the person in ‘baby talk’ or as if you are talking to a child.
- Use complicated words or phrases and long sentences.
- Glare at, or “eyeball” the person you are talking to.
- Begin a task without explaining who you are or what you are about to do.
- Talk to the person without eye contact, such as while rummaging in a drawer to select clothing.
- Try and compete with a distracting environment.
- Provoke a catastrophic reaction through unrealistic expectations or by asking the person to do more than one task at a time.
- Disregard your own non-verbal communication.
- Disregard talk that may seem to be “rambling”.
- Shout or talk too fast.
- Interrupt unless it cannot be helped.
- Attempt to touch or invade their personal space if they are showing signs of fear or aggression.

*Adapted from the regional Dementia Management Strategy (Australia 2001)*
Palliative Care in Dementia

The World Health Organisation describes palliative care as: “…the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological social and spiritual problems is paramount.”

Palliative care is relevant to all persons with chronic incurable disease and not only when death is imminent. Its possible application in dementia care has been recognised by some for many years and according to Black and Jolley 1990: “…palliative care is entirely suited to the care of persons with advanced dementia”.

A palliative care approach to dementia implies acceptance that the overall outlook for the disease is not cure and that quality of life and comfort are the most important considerations. By focusing on quality of life, health care practitioners may help patients and family members prepare for the future and address the physical and emotional needs of both patient and their families.

Dementia diagnosed early and uncomplicated by other illnesses can have a total duration of some ten years. The condition is often divided into mild, moderate and severe stages depending on the level of independence of the person. Mild dementia is when the person can continue to live independently, moderate is when support is needed for daily living activities and the severe stage is present when the person needs assistance with basic activities such as washing, dressing and food preparation. As the severe stage progresses the person will develop problems with feeding, starting with loss of appetite and volition to eat, moving on to difficulty swallowing and often culminating in aspiration of food into the respiratory system. This is often the natural endpoint of dementia where a bronchopneumonia causes respiratory failure and/or sepsis and death.

Decisions that may have to be faced as dementia progresses are invasive investigation of possible malignancies, artificial feeding, and resuscitation status. According to Hughes 2007 there are limited positive and possible or negative effects of cardio-pulmonary resuscitation and artificial feeding.

Good communication with all those involved with the patient’s care is vital and where possible the patient’s own preferences must be respected. Comprehensive needs assessments together with education of family and other professionals delivering care can enable realistic decision making.
Appendix 1: Resource Directory

1.1 - Memory clinics:

<table>
<thead>
<tr>
<th>Memory Clinics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dublin/Public:</strong></td>
</tr>
<tr>
<td>MIRA</td>
</tr>
<tr>
<td>St James Hospital, Dublin 8</td>
</tr>
<tr>
<td>Tel: 01 4162640</td>
</tr>
<tr>
<td><strong>Dublin/Private:</strong></td>
</tr>
<tr>
<td>St Patricks Hospital, Dublin 8</td>
</tr>
<tr>
<td>Tel: 01 2493200</td>
</tr>
<tr>
<td>Beaumont Hospital, Dublin 9</td>
</tr>
<tr>
<td>Tel: 01 8375400</td>
</tr>
<tr>
<td><strong>Clinics outside Dublin</strong></td>
</tr>
<tr>
<td><strong>Cork</strong></td>
</tr>
<tr>
<td>Cork University Hospital</td>
</tr>
<tr>
<td>Tel: 021 4920015</td>
</tr>
<tr>
<td><strong>Tipperary</strong></td>
</tr>
<tr>
<td>St Patricks Hospital, -Cashel</td>
</tr>
<tr>
<td>Tel: 06270325</td>
</tr>
</tbody>
</table>

Non Clinical Memory Assessment:
Healthy Living Centre, DCU, Dublin 9
Tel: 01 7007171
This does not require GP referral. Clients can present themselves.

1.2 - The Alzheimer Society of Ireland

Log on to: http://www.alzheimer.ie/eng/We-Can-Help for a full list of dementia-specific services in Ireland.

1.3 - Useful websites:
Dementia Services Information and Development Centre - www.dementia.ie
Emergency Response - www.emergencyresponse.ie
National Council on Ageing and Older People - www.ncaop.ie
National Centre for the Protection of Older People - www.ncpop.ie
Transport and Mobility Consultants - www.transportandmobility.ie
### 1.4 - Older People's Organisations

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Address</th>
<th>Contact Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age Action Ireland Ltd</td>
<td>30 Lower Camden Street, Dublin 2</td>
<td>Tel: (01) 475 6989 E-mail: <a href="mailto:info@ageaction.ie">info@ageaction.ie</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Irish Senior Citizen's Parliament</td>
<td>90 Fairview Strand, Dublin 3</td>
<td>Tel: (01) 856 1243 E-mail: <a href="mailto:seniors@iol.ie">seniors@iol.ie</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age &amp; Opportunity</td>
<td>Marino Institute of Education, Griffith Avenue, Dublin 9</td>
<td>Tel: (01) 805 7709 E-mail: <a href="mailto:info@ageandopportunity.ie">info@ageandopportunity.ie</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>National Federation of Pensioner's Associations</td>
<td>Carmichael House, North Brunswick Street, Dublin 7</td>
<td>Tel: (01) 873 5702 E-mail: <a href="mailto:nfpasec@eircom.net">nfpasec@eircom.net</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active Retirement Ireland (ARI)</td>
<td>1-2 Eustace Street, Dublin 2</td>
<td>Tel: (01) 679 2142 E-mail: <a href="mailto:fara@eircom.net">fara@eircom.net</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Older Women's Network (OWN)</td>
<td>All Hallows College, Grace Park Road, Drumcondra, Dublin 9</td>
<td>Tel: (01) 884 4536 or (01) 884 4537 E-mail: <a href="mailto:ownireland@eircom.net">ownireland@eircom.net</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carers Association</td>
<td>Prior's Orchard, John's Quay, Kilkenny</td>
<td></td>
</tr>
<tr>
<td></td>
<td>National Careline-Freefone 1800 24 07 24</td>
<td>Tel: (056) 772 1424/1800 24 07 24 E-mail: <a href="mailto:info@carersireland.com">info@carersireland.com</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Senior Help Line</td>
<td>Third Age Centre, Summerhill, Co. Meath</td>
<td>Tel: 1850 444 444 E-mail: <a href="mailto:info@seniorhelpline.ie">info@seniorhelpline.ie</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ICTU Retired Workers' Committee</td>
<td>32 Parnell Square, Dublin</td>
<td>Tel: (01) 889 7777 Web: <a href="http://www.ictu.ie">www.ictu.ie</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sonas aPc</td>
<td>St Mary’s, 201 Merrion Road, Dublin 4</td>
<td>Tel: (01) 260 8138 E-mail: <a href="mailto:sonasapc@iol.ie">sonasapc@iol.ie</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Irish Association of Older People</td>
<td>Room B15, UCD, Earlsfort Terrace, Dublin 2</td>
<td>Tel: (01) 475 0013 E-mail: <a href="mailto:iaop@oceanfree.net">iaop@oceanfree.net</a></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Third Age Foundation</td>
<td>Third Age Centre, Summerhill, County Meath</td>
<td>Tel: (046) 955 7766 E-mail: <a href="mailto:info@thirdage-ireland.com">info@thirdage-ireland.com</a></td>
</tr>
</tbody>
</table>
Helping You Understand Senior Care Issues

As Ireland's trusted source of home care for seniors, Home Instead Senior Care is committed to helping people better understand senior care issues. We have published a number of guides designed to provide trusted information about issues such as dementia care.

The following free publications are available from any Home Instead Senior Care franchise office. You can also call 1890 930 013 to order a free guide.

- The 40-70 Rule
  A Guide to Conversation Starters for Adult Children and Their Senior Loved Ones

- Beat the Break
  A Guide to Osteoporosis, Healthy Bones and Fall Prevention

- Helping Families Cope
  A Dementia and Alzheimer’s Guide for Family Caregivers

- Running on Empty
  Who cares for the Caregivers?
About Home Instead Senior Care

Home Instead Senior Care is Ireland's trusted source of home care for seniors, allowing them to continue to be independent and live in their home for longer than otherwise possible.

Since 2005, the Home Instead Senior Care franchise network in Ireland has been devoted to providing the highest-quality senior home care. Compassionate Home Instead CAREGivers are an invaluable resource helping families eliminate worry, reduce stress and re-establish personal freedom. From Alzheimer's and dementia support to respite care and companionship, Home Instead Senior Care and its seventeen locally owned and operated offices are ready to help you through this difficult time.

Home Instead Senior Care was also the first home care organisation in Ireland to be a preferred provider for the Health Services Executive and the first to have a contract with them for the provision of enhanced home care services.

The company was also named the 2009 "Outstanding Business of the Year" received the 2008 "National Small Business Service Award" from the Small Firms Association. It was also named Ireland's "Best Emerging Franchise" in 2006.

For more information, contact:

Home Instead Senior Care

Tel: 1890 930 013

Web: www.homeinstead.ie

For any queries regarding this booklet please contact Joanne Flood at joanne.flood@hisc.ie