A practical guide for supporting people with Dementia

Developed by East Sussex County Council Inter-agency Dementia Working Groups
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Introduction

East Sussex has one of the highest dementia rates in the UK. We are committed to doing all we can to help people and their carers live well with the disease.

This Guide has been produced to provide information about dementia to support people who have been diagnosed with the disease, their carers and people who work in this area. We hope that it will also help increase awareness and understanding of the disease and its effects.

Keith Hinkley
Director of Adult Social Care
East Sussex County Council
1. **What is it like for you to live with dementia?**

Dementia has probably created emotional and practical challenges in your daily life. You have used your usual coping skills and capabilities to deal with these. We want this guide to help you discover new ways of living your life as best you can. This is organised around four key principles which are widely regarded as important to the wellbeing of people with dementia and the people in their lives.

1. **Knowledge about dementia is important to understanding changing reactions and behaviours.**
2. **Active involvement of family and friends can help people with dementia feel valued and maintain their quality of life.**
3. **Distress and behaviours that are challenging can be reduced or prevented through improved communication, the physical environment and activities.**
4. **People with dementia should be able have the care they want respected as they come towards the end of their lives.**

1. **What is Dementia?**

Dementia is a collective term for symptoms which include:

1. Memory loss
2. Personality changes
3. Understanding difficulties
4. Communication difficulties
5. Reduced judgement and reasoning
6. Reduction in skills and abilities needed to carry out daily routines such as washing, dressing and cooking.
These symptoms worsen over time, although the symptoms and rate of progression varies with each person and type of dementia. This changing condition has serious implications for the individual as well as their family and friends. In recent years there has been an emphasis on supporting people with dementia, to encourage them to maintain an active life and use their past skills to improve their health. The way we think about dementia continues to develop with personalisation – which means putting the individual before the illness and doing what is best for each person.

**Types of Dementia**

There are about 200 types of dementia. The most common types are:

- Alzheimer’s disease.
- Vascular dementia.
- Frontotemporal dementia.
- Dementia with Lewy bodies.
- Mixed type dementia – features of Alzheimer’s and Vascular dementia or Lewy Body Dementia.
### What is happening in the brain

Widespread deterioration as the result of abnormal calcium-like clumps (plaques) and tangled bunches of nerve fibres (tangles) resulting in shortage of key chemicals and loss of nerve cells.

### Symptoms

People with early stage Alzheimer's may experience forgetfulness and difficulties with finding the right words. As the condition progresses, they may experience:

- Loss of memory and confusion.
- Changes in mood and personality.
- Problems with language and reasoning.
- Taking longer to complete everyday tasks and learn new tasks.

### Progression

Gradual onset, which becomes more progressive as increasing areas of the brain become damaged over time, leading to more severe symptoms.
<table>
<thead>
<tr>
<th>Type of dementia</th>
<th>Vascular dementia</th>
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</thead>
<tbody>
<tr>
<td>What is happening in the brain</td>
<td>Caused by damage to the blood supply to the small vessels in the brain, as the result of a blocked or damaged vascular system. Typically the result of a stroke or series of tiny strokes (TIA’s or Transient Ischemic Attacks) which causes patchy and localised damage.</td>
</tr>
<tr>
<td>Symptoms</td>
<td>Symptoms may be similar to other types of dementia, such as Alzheimer’s, but people with vascular dementia may particularly experience:</td>
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<td><strong>Mild stage</strong></td>
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<td></td>
<td>- depression, restlessness and anxiety,</td>
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<td>- episodes of severe confusion, and</td>
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<td>- obsessive behaviour.</td>
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<td><strong>Moderate stage</strong></td>
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<td>- physical difficulties, such as weakness and unsteadiness</td>
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<td>- hallucinations or visual mistakes (seeing the outline of a tree as a person), and</td>
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<td>- problems with concentration and language.</td>
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<td><strong>Severe stage</strong></td>
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<td>- loss of memory,</td>
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<td>- seizures,</td>
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<td>- incontinence, and</td>
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<td></td>
<td>- increasing physical weakness, unsteadiness or paralysis (often related to strokes).</td>
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<tr>
<td>Progression</td>
<td>Onset can be sudden or gradual and then typically follows a ‘stepped’ progression, with symptoms remaining at a constant level for a time and then suddenly deteriorating.</td>
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<tr>
<td>Type of dementia</td>
<td>Frontotemporal dementia (<em>This includes Pick's disease, dementia associated with motor neurone disease and frontal lobe degeneration</em>) Occurs less frequently than other types of dementia, although it is a significant cause in younger people under 65.</td>
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<tr>
<td>What is happening in the brain</td>
<td>Caused by damage to the frontal lobes of the brain.</td>
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<tr>
<td>Symptoms</td>
<td>The most common are changes in mood and personality. There are a variety of symptoms which will vary from person to person:</td>
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<tr>
<td></td>
<td>o Unaware of difficulties, such as failing to appreciate risks.</td>
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<td>o Lack of empathy, such as making unkind comments or upsetting others.</td>
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<td>o Unable to control responses, leading to aggressive and sexual comments and behaviour.</td>
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<td>o Impulsive mood and behaviours, such as suddenly doing something ‘out of the blue’.</td>
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<td></td>
<td>o Problems with language, such as talking around a topic or reduced speech.</td>
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<td>o Lack of flexibility.</td>
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<td>o Repeating actions and phrases over and over again.</td>
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<td>o Poor planning and decision-making.</td>
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<td>o Apathy and difficulty in taking the initiative.</td>
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<td></td>
<td>o Easily distracted.</td>
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<tr>
<td>Type of dementia</td>
<td>Dementia with Lewy bodies (DLB)</td>
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<tr>
<td>What is happening in the brain</td>
<td>Lewy bodies are small protein deposits found in the nerve cells.</td>
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<td>Symptoms</td>
<td>Has been linked with Parkinson’s Disease (tremors, muscle stiffness, slow movements, balance and gait difficulties, restless leg). Overlapping symptoms with Alzheimer’s disease in the early stages but increasing problems with:</td>
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<td>- Dramatic and frequent fluctuation in alertness, understanding and mood.</td>
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<td>- Hallucinations, usually of people or animals.</td>
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<td>- Increased sleep during the day with restless nights.</td>
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<td></td>
<td>- Prone to falls, fainting or ‘turns’.</td>
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<tr>
<td>Progression</td>
<td>Rapid progression</td>
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**Learning Disabilities and Dementia**

People with learning disabilities are at risk of developing dementia at a younger age and people with Downs Syndrome are at particular risk of dementia, usually Alzheimer’s Disease. The symptoms and progression of the dementia for people with a learning disability may differ from those described above. Please see the Alzheimer’s Society factsheet on Learning Disabilities and Dementia for information on assessment and support. Please see further reading link at the end of this document.
2. How can family and friends be actively involved?

When someone is diagnosed with dementia it can be a very difficult and unsettling time, both for the individual and for his or her family. This is a life changing experience and people need help and support to adjust to this. It is important that family members feel adequately informed and supported and able to seek help when they need it. The next section gives some ideas on how you can be helpful to the person with dementia and how you can keep involved, even if they move into residential care.

**Using life stories**

Family and friends can use personal stories to help the person with dementia communicate and help others get to know someone better. Life stories can be used to support people living at home or living in residential care.

Life stories can be used to:

- Promote conversation and as a pleasant activity.
- Reminisce and review past events in ways that can bring people closer together.
- Explain what is important to a person and why someone might be acting in particular ways so that others can meet their needs.

There is no one way of developing someone’s life story but the important thing is to help people record and share their life story in whatever way is best for them. You could create something together, such as a book, photo album, collage, pictures, memory box, or audio recording that contains the memories of the important events in a person’s life before you met them and during your lives together. Be as creative as you like!
Life stories are not an end in themselves and are never finished. Using life stories is an ongoing process and an opportunity for sharing and talking about things in whatever way or whichever order feels right. It is something that can be discussed and reflected upon in different ways at different times.

When developing and discussing someone’s life story it is important to:

- Make time for listening and understanding.
- Be sensitive to what the person wants to say and how he or she wants to say it, without correcting or judging.
- Be aware that strong emotions, both positive and negative, could be expressed.
- Give reassurance or use distraction by changing the topic if you feel you need to.

**Involvement in care homes**

In order for care home staff to deliver care that is unique and personal, family members are essential in providing information about a person’s background, personality likes and dislikes and how they cope.

The relationship between family and staff in the care home is not only crucial to the wellbeing of the person with dementia but can be important in reducing the strain and pressures that family members experience. Many staff are experienced at understanding what family members have gone through in deciding and supporting the person with dementia to move into a care home.

There can be differences of opinion about the way people think things should be done in the interests of the person with dementia. When communication feels difficult, it can be important to bear in mind that you have the same goals and wishes and the important thing is to be able to talk about these without criticism or judgement.
Tips for staying involved and confident in your caring role:

- Doing small things with the person with dementia, such as sorting through their photo album, can have a positive impact.
- Maintain contact, even if it is difficult because of other commitments or distance, through phone calls and sending letters or photos.
- If you find visits stressful, ask if you can take the person out, for example on a picnic, to the beach or for a coffee or tea.
- Talk with the staff about helping with hands-on care tasks, such as mealtimes or take part in activities organised by the staff.
- Make sure you are consulted when decisions need to be made about the person’s care.
- Be confident about expressing your views and wishes in constructive ways.
3. How to improve communication, the physical environment and activities

Communication

Communication is more than just words. It includes non-verbal communication such as body language and actions which are used to express feelings and enable people to connect with each other.

When you work with an individual on their personal histories and stories, you should note what descriptions they use and how they express themselves. They may also use metaphors to describe their thoughts and feelings. This information is useful in understanding their non-verbal communication.

Barriers to communication

People with dementia have difficulties communicating their wishes and needs and rely on the kindness and understanding of their carers, family, and friends to support them and to help them through the barriers which arise.

These barriers can include the individual developing memories of events which never took place. Alternatively, the memories may be real (such as a childhood picnic in a park) but the person believes the event took place yesterday or on a beach. Producing these false memories is call ‘confabulation’.

Another example of a barrier is where language is damaged by changes in the brain, known as ‘dysphasia’. ‘Expressive dysphasia’ is where the understanding of the individual remains intact, but conveying messages is impaired, causing considerable frustration.

Communication barriers can be put into two categories; social psychological, and technical.

Social psychological barriers refer to a limitation in the skills of those people around the person with dementia to communicate with them, or an incorrect view of how they themselves are able to communicate.
The person with dementia may start communicating in a way that uses simpler words than they have used before, as well as a greater use of non-verbal mechanisms.

There would be a need for those around the individual to learn this new way of communicating. If they do not, the person is likely to develop feelings of isolation, loneliness, fear and sadness.

Technical barriers are those which arise from the damage to the brain that has been caused by the dementia. These will centre on speech and language, with an inability to find words to express themselves or to understand what those around them are saying in order to be able to respond.

In these instances, the person may resort to using similar words (cart instead of car) or use phrases from their past. This adds extra importance to knowing their personal history, to understand what they are trying to say.

**Improving communication**

You can make communication easier for people with dementia by following these tips for the conversations you have:

- Remember any limitations, such as hearing difficulties.
- Make sure they can see and hear you clearly (reducing background noise will help).
- Be on eye level with the person, standing over someone seated can be intimidating, as can being too close to the person.
- Speak clearly, using simple vocabulary and not jargon.
- Use concise, clear sentences.
- Be aware of the person’s body language and your own. If you have tense facial expressions or sudden movements, you are likely to cause them distress and upset them.
- Avoid negative statements, for example “Don’t”. Try to encourage positive words.
• Avoid open ended questions.
• Let the person finish their own sentences unless they ask for your help.
• Be mindful of your own tone and how you are speaking and make sure you have their full attention before you speak.
• When responding to a question, make sure you answer clearly and completely. It can take a person with dementia some time to form questions and you should try to avoid the need for them to ask additional ones.
• Enjoy the conversation and use humour to share this enjoyment; if appropriate.
• Be patient. When responding to repeated questions, reply as if it is the first time you have been asked.
• Try to accept what is said to you rather than argue about it. This will cause confusion and stress.
• Use facial expressions and, if appropriate, written communication to enhance understanding.

**Creating the right environment**

Creating the right environment is something that should be done in addition to, and not instead of, spending time with people and listening to them. A good environment supports the needs of people with dementia, promotes independence, stimulation, and reinforces personalities. A poor environment can disorientate a person, make them feel isolated, disengaged, and be perceived as scary.

A person with dementia may have problems perceiving objects correctly, not being able to separate something from its background (a white light switch on a white wall), or misjudging distances. By introducing a variety of colours, people will find it much easier to locate things and it will reduce the risk of accidents.
Failing memory can lead to spatial awareness problems, making people lose direction and become lost. Adaptive equipment exists to help individuals who have physical problems with balance, motor control, mobility and vision. Other equipment exists to aid with memory loss as will devices used for warnings or safety (including alarms which sound when a door opens or electronic candles). Nonslip rugs and grab bars within bath and shower rooms can help reduce the risk of falls.

Equipment to assist with meals, and thereby enabling individuals to maintain an element of their independence when eating, include plates with suction cups underneath to avoid sliding, cutlery with especially design grip handles and cups with two handles to aid holding drinks.

It should be remembered that not all physical support that is required is as a result of dementia. Many conditions are due to the ageing process, such as arthritis. This can lead to difficulties in moving around the home and getting on and off of furniture. Items such as tap turners, raised toilet seats, grab rails and other assistive technologies can aid people in their daily lives and promote independence. Consideration, however, should be given to the fact that people with dementia may forget what these aids are for or how to use them. Visual and written prompts can be added to enable people to make the most of any adaptations that have been made for their benefit.

**Make it easy to find things**

The combination of dementia and sight problems in older age can make it difficult to understand the world around you.

**Highlight key items**

Keep essential items in view e.g. cup, kettle, tea bags. You may leave these out on the kitchen surface or you can use a shelf or glass fronted cupboard. Use clear jars for coffee, tea and sugar. Reduce unnecessary clutter so that it is easier to find things.
Label drawers or cupboards where other essential items are kept. You can make your own labels with post it notes or buy picture labels from specialist suppliers.

**Increase light to twice normal levels in task areas**

Increase light to twice normal levels in task areas especially kitchens and bathrooms. Let more light in. Keep curtains clear of windows, cut planting near windows. Increase the number of light sources and wattage of bulbs. Make sure you check your lampshades are safe if you are increasing the wattage of bulbs. People can become disinterested in activity just because they cannot see easily. Highlight light switches with stick-on contrasting labels.

Regular exercise and exposure to daylight has been proven to reduced frustration, anxiety, depression, and aggression. It can also improve sleeping patterns.

**Make sure they have their address and contact number**

Make sure they have their address and contact number in a pocket if they are intent on going out. GPS trackers or mobile phones can also be used to track people.

**Keeping occupied – creating distractions**

People with dementia can become bored, restless, and agitated very quickly. Finding ways to distract them can help.

**Light therapy**

Daylight lamps, extending curtain rail beyond edges of windows, cutting away planting that overshadows windows, and regular access to outdoors, can all have a calming effect.

**Work out what promotes calm**

Music chosen carefully according to the person’s individual tastes can be therapeutic.
Use smell
Cooking smells can stimulate appetite or lavender can be relaxing.

Touch
Affection, hugs, holding hands, massage, doing hair, manicure, using hand cream.

Animals and pets
Being in the company of animals can stimulate positive memories of childhood pets and bring comfort and pleasure.

Activities designed for people with dementia
Meaningful and well structured activities for people with dementia are essential for helping them to maintain skills and abilities, engage with others, introduce variety and enhance wellbeing and quality of life.

Activities can be a daily opportunity for self expression, communication and sharing memories. Individuals with dementia should be given a choice of activities which focus on what they enjoy doing and aim to expand their existing hobbies. For example, someone who likes to sketch may be encouraged to try painting.

Activities can:
- Create a sense of calm and reduce restlessness,
- Reinforce self worth and value within a person, and
- Promote wellbeing and enhance quality of life.

How to help someone with dementia who is in pain or distress
If you are giving care or support to somebody with dementia, particularly as it advances and their ability to communicate reduces, you may find that they sometimes behave out of character. This can be displayed in different ways, including being agitated, frustrated, confused, wandering, anxious, pacing, calling out, aggressive, or fearful.
Behaviour like this can be alarming and challenging to cope with. However it is not something that’s “just part and parcel” of having dementia or that nothing can be done about. It’s likely that something is causing this behaviour. The behaviour may well be a symptom or a sign of distress, or an attempt to communicate an unmet need, and not an untreatable part of the disease.

And if you can find out what the cause is, you might be able to do something about it.

It could be that they are in pain or discomfort. People with dementia can still experience pain, although they might find it hard to tell you what’s troubling them. Or it might be something else that’s causing them distress.

**Knowing whether someone is in pain or distress**

There are simple things you can do:

- Ask the person what the matter is
- Listen to them
- Observe their behaviour and what’s going on
- Act on what you’ve seen and heard

It can be hard to know exactly what’s going on, particularly when somebody has advanced dementia and finds it very hard to communicate clearly. But there may be clues in how they are behaving.

- What does their face look like? Are they grimacing, grinding, or clenching their teeth?
- Are they rubbing, pointing, or pulling at a particular part of their body?
- Are they irritable, crying, or tearful?
- Or groaning? Are they shouting or screaming?
- What is their body language like? Are they stiff, or rocking, or perhaps guarding part of their body?
• What happens when they move? Are they less mobile or moving differently? Are they pacing, unable to settle for long, restless, or fidgeting?
• Are they looking fearful? Do they seem to be seeing things or to be frightened?
• Has their appetite changed?
• Has their breathing pattern changed?
• Check to see if the person has a temperature. There may be other physical clues: for example, have they recently fallen, do they have an infection, or are they constipated?

Some examples of things that might be causing pain or distress

• Sore mouth, toothache, or ill-fitting dentures
• Earache
• Being lifted or moved in an uncomfortable or painful way
• Difficulty in going to the toilet or a urinary tract infection
• Painful joints
• Painful sores
• Uncut finger or toenails
• Being in an uncomfortable position or the same position for a long time

People with dementia can feel pain, and there are things you can do to treat it.

It depends on the severity of the pain, but things that might help include the following:

• Changing their position
• Touch, massage, presence and reassurance
• Cool compress or warmth
• Using easily available painkillers, such as paracetamol

However sometimes this may not be enough, and it may be necessary to speak to a doctor or a dentist or ask for prescription painkillers or use them if you already have been given them.
This progression from weaker to stronger types of pain relief is sometime called the “analgesic ladder”.

You may need to act as an advocate or supporter for the person with dementia to make sure other pain medications are considered or tried.

**Tips: There are different ways of delivering pain relief.**

For example patches can be used if it’s difficult for the person to take them orally.

Some different painkillers can be taken at the same time (ask your doctor or pharmacist about this).

Pain relief for moderate and severe pain will require medical advice and prescription.

Some pain relief can carry side effects, for example constipation. Take medical advice about this.

**Other causes of distress or challenging behaviours**

There are times when people with dementia develop symptoms that result in distress or behaviour that we find difficult to manage. In these instances, the individual should be offered an assessment at the earliest opportunity to understand what issues may trigger, aggravate or reduce this behaviour. Assessments should be carried out by a Community Mental Health Team and a person’s GP can help to arrange this.

The assessment should be thorough and include:

- Side effects of any medication being taken
- Any potential pain or discomfort that had not previously been detected
- Any indicator or history of depression and psychosis
- A biography of the person, including cultural identity, religious beliefs, or spirituality
- Professional analysis of behaviour and functionality in relation to specific skills
• Supported input from care workers and carers
• Issues arising from within their physical environment.

Research has highlighted that the following factors may potentially lead to behaviour changes:

• Feeling frightened
• Personal history and experiences
• Pain and discomfort
• The response of other people to the person’s behaviours
• Misunderstanding their environment
• Over-stimulating or under-stimulating environment
• Not being able to communicate or make others understand them
• Feeling that the care they are receiving is controlling.

The Alzheimer’s Society recommend supporting people who display behaviour we find challenging in the following way:

• Respond calmly to any behavioural changes
• Find out what triggered the behaviour
• Avoid or minimise these triggers or change others’ responses to the behaviour
• Acknowledge the distress and/or find alternative activities to help the person move on from their distress.
4. End of life care and dementia

In the later stages of dementia the person’s memory loss becomes more severe to the extent of them being unable to recognise themselves as well as other people and they withdraw into their own world with only occasional flashes of recognition. The ability to communicate verbally and through facial expression becomes more difficult. This can create problems as the lack of facial expression can be misinterpreted as a lack of understanding or that the person is not feeling any pain. The person increasingly loses their ability to understand what is being said and to make sense of their surroundings. They may become unable to walk and manage everyday tasks often resulting in them becoming confined to a chair or bed. The desire to eat or drink reduces and weight loss occurs.

The individual’s quality of end of life can be enhanced if the individual’s values, wishes, and preferences are known to those involved in their care. This can be achieved by ensuring that the person with dementia is given the opportunity to discuss their wishes and preferences regarding end of life care early on in the illness, when they still have the capacity to make informed decisions. Knowing and recording these will help the person’s relatives or carers to have confidence in any decisions they may need to make as the dementia progresses and circumstances change.

Although it may not be possible to comply fully with the person’s wishes and preferences, an Advance Care Plan (ACP) and an understanding of what is really important to the individual will enable those around them to make better informed decisions within the limitations of what is possible.

The ACP also enables services to plan ahead and provide appropriate support to meet the individual’s wishes as far as is possible and practicable. The person with dementia may also wish to have an Advance Directive to Refuse Treatment (ADRT) which
specifies those things they do not wish to happen. Having an ACP and or ADRT in place can help to avoid the individual’s final days or hours being in an inappropriate environment.

You may also wish to consider putting in place a Health and Welfare Lasting Power of Attorney. This gives an appointed person (the Attorney) the power to make decisions regarding health and welfare on behalf of another person when they lack the mental capacity to do this for themselves.

More information

For further information contact your local Alzheimer’s Society Dementia Advisor.

Further reading:
Alzheimer’s Society ‘My life until the end- Dying well with dementia’ (October 2012)

For information on learning disabilities and dementia
http://alzheimers.org.uk/factsheet/430

For guidance on creating a life story:
http://www.dementiauk.org/assets/files/info_and_support/Dementia_UK_Life_Story_Template_final.doc
Getting more copies of this leaflet
You can get all our leaflets in large print, easy read format, in Braille, on audio tape or CD, or in other languages. They are also available in PDF form, which you can download from our website at eastsussex.gov.uk

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