

Advanced Dementia Consultation

Developing the 8 Pillars Model of Community Support

Introduction

Advanced dementia is intensive and complex. Individual experience will vary according to a range of factors that will be unique to each person. However, the progressed illness means that many of the distinctions between the different types of dementia have diminished by the time advanced illness is reached.

Alzheimer Scotland's 8 Pillars Model of Community Support sets out an integrated and comprehensive approach to support people living with dementia as their needs progress. This paper seeks the views of key stakeholders in order to develop the 8 Pillars Model to support people living with advanced dementia.

Advanced dementia

The global deterioration scale (Reisberg 1982) provides an overview of cognitive decline and the key transitions in the progression of dementia. This consultation is concerned with the needs of people living with moderately severe and very severe cognitive decline according to this scale:

- Severe cognitive decline (stage 6: moderately severe dementia): awareness of people and surroundings will be diminished. More assistance will be required with activities of daily living such as bathing, eating and toileting. The person may begin to show increased anxiety and possibly develop delusions, hallucinations or obsessions. Daily rhythm is frequently disturbed, with sleep during the day and awakened at night.
- Severe dementia (stage 7: severe dementia): the ability to speak will be very limited and may be lost completely. The person will require assistance to walk and to sit up. There will be loss of urinary and bowel control.

Just as the lived experience of dementia varies considerably between individuals, so does the experience of dying with dementia. People can become terminally ill at any time during the course of dementia as a result of co-morbid illness. People reaching advanced dementia become less able to cope with infections and other physical problems as a result of the progressed illness, with many people dying as a result of pneumonia.

Cox and Cook (2002) provide categorisations to outline the different ways in which people with dementia die:

- (1) people who reach the end of life with dementia but die of some other identifiable condition (e.g. cancer) at some point on the pathway through dementia
- (2) people who reach the end of life due to a complex mix of mental and physical problems but where the effect on brain functioning is not as advanced
- (3) people who reach the end of life and die of the complications of dementia, such as end stage dementia.

We have provided the following categorisations as an approach to defining the different phases during advanced dementia:

- **Moderately advanced dementia:** the person begins to experience more intensive, and possibly a greater number of, symptoms than before. The need for support and care increases and the person will require continuous support.
- **Advanced dementia:** the type and level of symptoms and the person's experience shows that they are clearly experiencing advanced illness. The person will require intensive support.
- **End of life:** people can become terminally ill at any time during the course of dementia as a result of co-morbid illnesses. People reaching the end of life with advanced dementia will have a range of different experiences.

Q1: Are these three categorisations helpful in outlining the experience of advanced dementia?

Speech and Language Therapists (SLTs) work with people at every stage of dementia, including those living with advanced dementia. How fast dementia progresses will depend on the person and also the type of dementia they have. Each person is unique and will experience dementia in their way. Whilst categorisation may be useful, it is important to recognise that a person's experience of these categorisations will also be unique.

It is therefore important to give consideration to:

Distinguishing between the categories: It can be difficult to distinguish between the different phases – how do you anticipate people should distinguish between 'moderately advanced', 'advanced' and 'end of life'? It is particularly difficult to distinguish between 'moderately advanced' and 'advanced', given the lived experiences of advanced dementia.

Decision-making: Who would be making the decision on whether a person fits a certain category and whether the person's dementia was categorised as 'moderately advanced', 'advanced' or 'end of life'?

Overlaps between the categories: There can be overlaps between the categories. Different types of dementia can get very disabling and advanced in some ways, but not in others. You can also get someone with a very advanced dementia and is still functioning relatively well.

Generalisations: The fact that having a 'range of different experiences' applied to everyone is not very helpful.

Include information on level of care and support: The categories fail to capture enough information on the level of care and support required during each phase. The categories should be revised to include this detail. For example, what type of support would be required at the different stages?

Providing examples: It would be helpful to provide examples at each stage.

Symptoms of advanced dementia

The distinction between the different illnesses of dementia becomes blurred by advanced illness as a result of almost all brain systems that support cognition and function becoming impaired (Rabins & Black 2010). The set of symptoms caused by advanced dementia are set out under the headings below:

Physical experience

Symptoms that require medical attention will be to the fore during the advanced illness, with physical health demanding increasing attention as the illness progresses (Hughes et al 2007).

Gait disorder increases the risk of falls for people who are still moving about (ambulatory). Most people will become unable to ambulate without assistance and many become bed-bound irrespective of the preventative steps taken (Rabins & Black 2010).

Generalised spasticity and rigidity result in limited ability to generate spontaneous movement. This predisposes the skin breakdown and the development of pressure or decubitus ulcers (Rabins & Black 2010). Disorder swallowing is common. This limits oral intake and leads to malnutrition, aspiration of food and secretions into the lungs and aspiration pneumonia (Rabins & Black 2010).

In addition to the physical impact of advanced dementia outlined above, older people are more likely to have pre-existing health conditions that will combine together in a complex way (Prince et al 2013).

Communication

The person's ability to express themselves and understand others will be severely impeded by advanced illness. The ability to communicate by talking is lost as a result of impaired motor control of speech, apraxia and aphasia (Rabins & Black 2010). The ability to communicate is further impeded by gaze palsies, apraxia of eye movement and severe visuo-spatial impairment (Rabins & Black 2010). These conditions result in the person being unable to describe pain or express emotion and can act to detach the person from others. It also means the person is unable to look at people in their environment or recognise everyday items such as feeding utensils, further isolating the person from social interaction.

Psychological symptoms

Low mood and neuropsychiatric symptoms^a continue to be prevalent in advanced dementia (Kverno 2008). These symptoms stress and distress the person and are problematic for those providing care (Ballard & Aarsland 2009). Whilst these behaviours have traditionally been thought of in relation to symptoms of the disease, research has shown they can also be caused by attempts to communicate unmet needs (Stokes 2009).

^a Three main neuropsychiatric syndromes are (1) agitation: including symptoms of aggression, irritability, restlessness and pacing (2) psychosis: including symptoms of visual hallucinations, auditory hallucinations and delusions (3) mood disorder: including depression anxiety and apathy (Ballard & Aarsland 2009).

Q2: Do the sections on physical experience, communication and psychological symptoms provide an accurate overview of the symptoms of advanced dementia?

Dementia can cause:

- Communication difficulty for the person with dementia.
- Communication difficulty for carers.
- Eating, drinking and swallowing difficulties.

SLTs have the specialist knowledge and skills to directly assess and manage these problems. Communication problems occur in all forms of dementia and in the later stages these problems become increasingly challenging. The distinct section on communication is therefore especially welcome.

The RCSLT further suggests:

More information is required on eating, drinking and swallowing related difficulties within this overview of symptoms: There is a distinct heading on 'communication' and there should also be a separate heading on 'Swallowing, eating and drinking difficulties'. Difficulties with eating, drinking and swallowing are a recognised challenge for people with dementia, particularly in the later stages. 60% of those with dementia in homes for older people were found to have dysphagia (Steele et al, 1997). The need to assess and manage eating and swallowing difficulties and identify potential aspiration is important, particularly for those with more advanced dementia. Eating and drinking problems have well documented affects on physical health, but also adverse affects on self-esteem, socialisation and enjoyment of life including anxiety and panic during mealtimes. It is therefore important that a distinct and descriptive paragraph is included in this section. In this new distinctive section, it would important to state that with these difficulties a person can simply need one-to-one assistance or a longer meal time.

Consistent and clear terminology: With reference to the overview of symptoms, there are a number of terms that are medical/diagnostic and therefore may not be understood by all. It is important to consider this depending on the target audience for the information. Consistent terminology would also be useful. For example, it states 'physical experience' then 'communication', and then 'psychological symptoms' – this is confusing, because is it about experience, symptoms or both?

Changes required to communication section: The specific information given in the paragraph on communication is not an accurate reflection of a person living with advanced dementia. In particular, the RCSLT takes issue with the notion that someone can be unable to express emotion, which is not accurate during any stage of dementia. Descriptions such as 'unable to look at people in their environment' should also be revised. Even in the very advanced stages of dementia, it is unhelpful to use the term 'unable' because often it is about the need to support people to make these forms of communication and it is, for example, about supporting people to look at people rather than describing them as 'unable'. *People living with advanced dementia may make unsuccessful attempts to communicate, but that does not mean that people living with dementia stop being able to communicate. People living with advanced dementia are able to communicate and express themselves,*

sometimes in unconventional ways, and with the right SLT support, the person can be helped with their communication difficulties.

Further information on communication and stages of advanced dementia can be accessed here: <http://www.talkingmats.com/wp-content/uploads/2014/07/Dementia-CDS-v2.pdf>

Q3: Do you wish to outline any other symptoms of advanced dementia?

Yes, swallowing, drinking and eating difficulties require to be added in a distinct heading within the overview of symptoms of advanced dementia. See comments in Q2.

It is important also to mention:

New information to be added into communication section: Under the communication heading, more detail is required to mention perseveration, losing track of topic, impact on relationships and participation. It is also important to state within this category that what works best for a person with advanced dementia in terms of communication strategies and aids can change over time. For example, some communication support that worked well previously may have to change. Communication can become more non-verbal and interactive with advanced dementia.

Bereavement and loss: In psychological symptoms it is important to state that a person living with dementia is going through bereavement in terms of losing relationships and sometimes losing bits of themselves. Discussion often includes the relatives and carers sense of loss, but it could be helpful to include bereavement in the overview of symptoms of advanced dementia.

Understanding the lived experience of dementia

Advanced dementia is experienced in a physical way. Looking at the illness from a medical perspective can provide useful clues and predictors for the variety of physical symptoms that require attention (Hughes et al 2009). The lived experience of illness is determined by the interaction between individual factors and the overall context in which the person lives (WHO 2002). A common approach to understanding dementia is to look holistically at the medical, psychological and social aspects of the illness (Hughes 2011).

The 8 Pillars Model of Community Support follows a bio-psychosocial understanding of dementia in recognising that the experience of illness is influenced by a range of factors. The Pillars combine to honour the right to personhood, full citizenship and optimum participation in society for people living with dementia.



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Q4: Is the 8 Pillars Model the correct basis from which to develop an appropriate approach for advanced dementia?

The RCSLT has found the 8 Pillars Model of Community Support useful. The RCSLT produced a leaflet written by SLTs titled 'Speech and language therapy works for people with dementia that drew upon the 8 Pillars Model. This Model is useful because it involves helping carers understand the role they can play in aiding communication and working as an SLT with carers can be the most important aspect of speech and language therapy in the later stages of care. This is crucial because the listener has potentially to do more work than the person living with advanced dementia who is trying to communicate with them. Carers need to become skilled in being able to ask the right kinds of questions and asking questions that offer clear choices rather than complicated answers. The Model also helps to understand that community support needs to be proactive such as the helpful interventions that can be used to manage eating and drinking safely for people living with advanced dementia in particular. This of course can include environmental factors like noise or low light. Small changes for people living with advanced dementia can make real differences. The 8 Pillars Model helps to demonstrate this.

Some specific points for constructive reflection include:

- An issue that is often raised is the role of the Dementia Practice Co-ordinator, which requires further work and discussion.
- The use of the term 'Therapeutic Interventions' may raise expectations, and suggestions include a new label for that pillar called 'Enabling Strategies'.
- The model, as highlighted above, is promising and good. It does not, however, cover everything. It would work well alongside the World Health Organization International Classification of Functioning, Disability and Health, which provides a standard language and framework for the description of the complete range of health related states and experiences of health.
- A consistent approach is required, but it is worthwhile noting that not all the pillars may be as relevant or important in the end stages of dementia.

Q5: Do any of the Pillars become more important?

The Pillar that increasingly becomes more important during advanced dementia is:

Support for carers: The support for carers pillar becomes more important for advanced dementia, as noted in the answer to Q4. Communication difficulty has been described as one of the most frequent and hardest to cope with experiences for family carers (Egan et al 2010; Braun et al, 2010). It is important to remember that many carers report moments of great joy, pleasure and humour from their life as a carer (Searson et al, 2008) with effective communication and relationships playing an integral part in this experience.

In addition, the following Pillars become more important during this stage:

General Health Care & Treatment; Therapeutic Interventions; Personalised Support; Environment

Q6: Are any Pillars no longer relevant?

The Pillars all remain relevant, but they can change in the ways they are used with the advanced stage.

Q7: What additional Pillars may be required?

The 8 Pillars Model mentions support for carers and also mental health care and treatment. There should be a Pillar, or perhaps a distinctive mention in an existing Pillar, regarding **mental health support for carers, which would include bereavement and anticipatory planning support**. Family support and bereavement in the end of life is not mentioned at all in the Pillars.

A Pillar on **Dignity** could also be considered.

Currently there is no mention on **spiritual care and people's beliefs** within the 8 Pillars.

A final comment is that a **greater emphasis is required on communication and people**. The Dementia Practice Co-Ordinator Pillar needs to ensure there is coordinated communication between practitioners because this becomes of even greater significance during advanced dementia. For example, a decision may have already been taken by a person living with dementia regarding eating, swallowing and drinking that is significant for an SLT to know. This co-ordination is vital, because it is important to know what practitioners or key people are involved so that time is not wasted chasing this information. There is no mention of the **Advanced Directives** (ie the wishes expressed by the individual) in the Pillars and, again, it is crucial that everyone involved with the person living with advanced dementia is aware of the ADP and this information is accessible.

What principles and approaches to care should underpin the model?

Nuffield Council (2009) report on dementia ethical issues affirmed that a person with dementia remains the same equally valuable person throughout the duration of their illness embodied in their own physical being and held within the network of their relationships. Whilst the development and implementation of Scotland's National Dementia Strategy is underpinned by a rights based approach.

The principles and approaches to care are of key importance to ensuring these ideals are upheld. The key ideas on how care can be provided and the considerations that should be taken into account are outlined below:

Person-centred care

Person-centred care was first used in relation to dementia by Kitwood (Downs 2009). Person-centred care shifts the emphasis away from the illness and collection of symptoms to the subjective experience of the person with dementia. Rather than prescribing particular behaviours in particular contexts, it promotes an understanding of who the person is and respect for their dignity and wellbeing (Downs 2009).

Person-centred care is a much used term that has no one accepted definition, but can be articulated by the following four elements:

Valuing	Valuing the person and those who care for them. Promoting the right to citizenship and entitlements regardless of age or cognitive impairment.
Individuals	Treating people as individuals. Understanding that responses to neurological impairment will be affected by unique history, personality, physical and mental health and social and economic resources.
Perspective	Looking at the world from the perspective of the person with dementia. Recognising that each person's experience has its own psychological validity, that people with dementia act from this perspective, and that empathy with this perspective has its own therapeutic potential.
Social	Recognising all human life is grounded in relationships and that people with dementia need an enriched social environment which both compensates for their impairment and fosters opportunities for personal growth.

(Brooker 2007)

Whilst person-centred care highlights that all human life is grounded in relationships and promotes valuing both the person and those caring for them, its focus is primarily on the subjective experience of the person. The lived experience of dementia goes beyond the person with dementia, and the care they receive is dependent on the responses of others.

Relational approach

The wellbeing of the person with dementia is closely aligned to the relationships with those closest to them. The family carer has the same right to have their interests and wellbeing considered. The interests of the paid carer are also important to consider. This relational approach to understanding the interconnected relationship of care has been developed into the 'Senses Framework'. The Framework (Nolan 2004) is underpinned by the belief that all parties involved in caring relationships (person, family carers and paid or voluntary carers) should experience relationships that promote:

Security	To feel safe within relationships
Belonging	To feel part of things
Continuity	To experience links and consistency
Purpose	To have personally valuable goal or goals
Achievement	To make progress towards a desired goal or goals
Significance	To feel that you matter

(Nolan 2004)

Palliative care approach

Like person-centred care, palliative care is both a philosophy of care and an approach to care (Downs 2009). Palliative care is a spectrum from providing a baseline palliative approach to specialist palliative care for those with complex problems (Hughes et al 2006). Key concepts of a palliative care approach are:

Quality of life and dignity	Importance of whole person rather than the disease in managing pain and other symptoms.
Inter-disciplinary team approach	Holistic and inter-disciplinary approach for assessing and managing ongoing physical, psychological, social and spiritual aspects of a person's life.
Supporting family throughout illness and bereavement	Places emphasis on supporting families throughout the period between diagnosis and death into bereavement.
Applicability throughout course of illness	From diagnosis, guided by the principles of holistic care and quality of life. Help to enable people to face their own mortality.
Person-directed	Person with illness being in control of care, support and treatment.

(Downs 2009)

Whilst dementia is widely acknowledged to be an illness requiring a palliative approach, this approach does present some difficulties. The long-term nature of dementia makes it difficult to understand when the palliative care approach is appropriate. Related to this, the commonly held association which palliative care has with the end of life makes it a problematic term for people living with dementia. How palliative care sits with curative treatment is also complex.

Supportive care

Supportive care aims to defuse the problems outlined above in relation to palliative care and introduce a curative thinking approach where appropriate. There are likely to be ailments alongside the dementia where a curative approach is appropriate. Future advancements may also make curative intent more appropriate for dementia. Supportive care is set out within three levels of understanding:

Layer one	Screening and investigations ⇒ Diagnosis ⇒ Curative approaches ⇒ Life-prolonging treatments (within palliative care context to comfort with life prolongation being a concomitant) ⇒ Life-maintaining treatments ⇒ Death ⇒ Grief and bereavement.
Layer two	Takes a holistic approach with biological, psychosocial, social and spiritual approach being provided along the trajectory of the illness from investigation to grief. The importance of each type of approach will change throughout the different stages of illness.
Layer three	Situating supportive care within different contexts. Giving consideration to surrounding social and economic contexts, constraints, ethics, law etc.

(Hughes 2009)

Q8: What elements from the approaches outlined above do you feel are important in advanced dementia?

There are important elements from the approaches outlined from the perspective of speech and language therapy. The sections on person-centred care and the relational approach are described well. The section on palliative care is important, but the way it has been described in the consultation document has provided a very medical slant with a focus on managing symptoms.

The current policy agenda is clear in that services should be designed around the needs and individual choices of patients and their families. This philosophy was encompassed within the work of Kitwood (1997) and has been developed and expanded by a number of researchers and practitioners. The **notion of personhood with its emphasis on preserved ability and wellbeing encourages the belief that all people with dementia, at all stages, have something to communicate**. The better we know the person, the better we can understand their communication attempts – especially their non-verbals – during the advanced stage of dementia. More recently, emphasis has shifted from person-centred to relationship-centred care to highlight **the need to support both the person with dementia**

and those who care for them (Nolan et al, 2004).

Gorska et al (2013), when assessing the service-related needs of older people with dementia, identified **the need for increased access to non-pharmacological interventions, including speech and language therapy, as an essential element of high quality care to support identity and social engagement.**

James (2011) argues that **behaviour that challenges is often an attempt by the person to make sense of the environment or communicate an unmet need.** Through careful communication with the person, the caregiver can take steps to understand the hidden meaning concealed by the confusion and therefore take steps to reduce the incidence of behaviour that challenges.

It can clearly be seen that **optimising the communication skills of both the person with dementia and carer is a central theme** to providing high-quality relationship-centred care. Assessment and treatment should be individualised, should draw from the broad range of approaches available and should take account of the increasingly well-documented evidence regarding patterns of language breakdown in different forms of dementia (Snowden, 2003).

It is therefore essential that all people with dementia and their carers are able to access speech and language therapy if this agenda and philosophy is to be met locally.

The only further comment to add is that it is important to **focus on the quality of life rather than prolonging life** and knowing the Advanced Directive. Advanced planning is key here, as part of holistic care, and to understand the importance of not prolonging distress. The WHO definition is a support system helping people to live until they die with a focus on participation in life. This needs to be captured.

Q9: Are there elements missing? What are these?

The different approaches as outlined provide a comprehensive account of the principles and philosophies of care that underpin the work of SLTs.

Greater emphasis may be required on:

- Dignity
- Safety of the person living with advanced dementia
- A link to the relevant frameworks that health practitioners have to work within by law (EG The Public Bodies (Joint Working) (Scotland) Act 2014; the Adults with Incapacity (Scotland) Act 2000)

For example, the RCSLT produced a toolkit for practitioners in Scotland that provided communication access guidelines, advice and practical resources for those implementing the Adult Support and Protection (Scotland) Act 2007 so that people with communication support needs who are at risk of harm or who are being harmed can more easily access protection afforded by the Act.

It is available here:

Q10: Ethical approaches & dignity

What comments would you like to make on ethical approaches and respecting dignity in advanced dementia?

The RCSLT members work within the following ethical principles in accordance with the RCSLT's guidance on best practice in service organisation and provision (RCSLT, 2006):

- **Respect for autonomy:** enabling individuals to make reasoned and informed choices
- **Beneficence:** There will be some benefit to the individual
- **Non-maleficence:** the imperative to avoid doing harm
- **Distributive justice:** the notion that individuals in similar positions should be treated in a similar manner

SLTs have a role to play in respecting the individual with advanced dementia, and enabling them the best opportunity to communicate their wishes and needs to, and have their wishes and needs understood by, health professionals and family members. Providing SLT support for someone with advanced dementia will enable that person to communicate their choices for as long as possible. This can be done by, for example, SLTs showing family members and care or hospital staff the best ways to communicate with the person experiencing advanced dementia. SLTs are a vital link in protecting the dignity of the person living with advanced dementia.

Beyond these principles, RCSLT members' code of ethics espouses:

- the values of **personal and professional integrity**
- a commitment to **competent and effective practice**
- **care for the individual** who is the focus of practice
- **inclusion**
- **team-working**

Team-working in particular is important here because the best outcome for the person living

with advanced dementia is for the professionals and family members being able to work in an integrated manner to achieve what is best. Communication and swallowing challenges are the responsibility of the whole team – the role of the SLT is to empower and educate others as well as providing specialist input as appropriate.

To emphasise, there is a fundamental, basic human need to communicate that continues right up to the end of life and part of respecting that, is about respecting the person with advanced dementia. **Giving people opportunities to communicate right up to the end is vital**, and includes the person living with dementia making a contribution because people have an instinct to contribute. We need to enable that possibility to communicate. This would also include the person's capacity for different decisions and approaches to help include people in decision-making for as long as possible.

Training, including practice-based coaching, is required for staff and carers in order to fully understand communication needs, ethics and respecting dignity. Facilitating communication, for example, is essential to protecting dignity.

Q11: Awareness of spiritual needs

What comments would you like to make on awareness of spiritual needs in advanced dementia?

Spiritual needs are often overlooked due to other difficulties being addressed for the person who is living with advanced dementia. An awareness of spiritual needs is not something that should simply crop up at the last stage, and it should be embedded in the care pathway right at the beginning in order to make it work the person and to ensure that practitioners and others keep looking at the person first – the person is more important than the dementia. In the experience of SLT practitioners, individuals living with dementia have awareness and views on spirituality even at the later stages.

Training is also required in order to understand and respect an individual's spiritual needs.

Q12: End of life

What comments would you like to make on end of life in advanced dementia?

The RCSLT recommends that end of life care should include specialist speech and language therapy support for feeding and swallowing problems. Input may also be needed to ensure that the person with dementia can make their needs known in the context of restricted communication abilities, access to and support from speech and language therapists will be crucial.

In the experience of SLT practitioners, end of life can often be a taboo subject. There can be issues around whether to feed or not, but it is important to listen to the person living with advanced dementia and also be more open with family and carers about whether someone

might be dying. Practitioners may not always know, but it is important to be open about it.

It is also useful to consider advanced care planning and how that can work in different settings during the consideration of end of life in advanced dementia. The entire team needs an understanding of end of life wishes and everyone needs to be co-ordinated in line with that person's wishes, so that the same pathway is followed by all those involved. SLTs have an important role here in communicating back to the whole team about how the person living with advanced dementia is expressing themselves.

See Scott Murray's important work at Edinburgh University:

<http://www.nutshell-videos.ed.ac.uk/scott-murray-livingdyingwell/>

What issues need to be addressed and what should the responses be?

Understanding of who is living with advanced dementia and the support they require

The implications of living with dementia extend beyond the person with the diagnosis. Whilst their experience will differ, the person and those closest to them may be thought of as living with dementia. Nuffield Council (2009) advocate paying close attention to the autonomy^b and wellbeing of the person with dementia and those who are providing their care. This is seen as important as each person matters in their own right and the wellbeing of the person with dementia will be closely aligned to the wellbeing of those around them.

In advanced dementia the care required is complex. If the person is living at home it is likely a significant proportion of their care is provided by family members. If the person is living in a care home the majority of their care is likely to be provided by care workers.

Q13: How accurate is this outline of living with dementia?

The RCSLT considers this an accurate outline of living with dementia.

SLTs work with the person living with dementia and those around them providing care, whether family members, health and social care staff, carers, social workers and so on. Support is required for the person living with dementia and support is also required for professionals such as home and social care staff. SLTs have helped work colleagues understand the communication needs for people living with dementia who continue to work; give care home staff guidance on how best to interact with people living with dementia to help the patient understand as well as care home staff better understand the patient. It cannot be stressed enough how important it is to provide support to the person living with dementia as well as those around them. Communication difficulty can be exhausting for the

^b Autonomy is seen as 'relational' in that a person's sense of self and self-expression should be seen as being firmly grounded in their social and family networks. When autonomy is understood in these terms, in order to support a person's autonomous wishes and values, it will be necessary to support the whole family and social structure (Nuffield Council 2009).

person with dementia and affects their identity and relationships.

There are also situations where there can be a combination of care being provided by family and a formal care package being delivered. In this context, person-centred care becomes of utmost importance in order to fully understand the individual's needs and patterns of presentation, especially as there may be frequent changes in staff members who provide formal care.

Q14: How should people living with advanced dementia be supported?

The RCSLT believes that any person with a communication problem or with dysphagia has a right to access a professional with expertise and support in these areas.

SLTs have an increasingly recognised and well-documented role in providing services for people with dementia. However, there has been a lack of consistency in service development within the NHS and wide variability in service provision remains. It is of concern that there remain many parts of the UK where people with specific communication or swallowing needs associated with their dementia are not able to access a specialist speech and language therapy service.

Commissioners, decision makers and service providers, who are aware of the needs of their local population, should ensure there is access to speech and language therapy services to meet those needs.

In addition, there is a need to ensure that carers are provided support for being themselves as well as being a carer. Just as we need to remember that a person with dementia is a person, the carer is not just a carer but a person in their own right with their own needs too.

Q15: How should the needs of everyone be responded to?

People with dementia and their carers have a range of needs in communication, safe eating and drinking which should be met by individuals with the appropriate clinical expertise or those who have been trained by people with that expertise. It is also important not to make assumptions around what people's needs are. People's needs should be responded to effectively, and timely, ensuring the staffing and provision is there to meet those needs.

Refer also to answer to Q14.

Communication in advanced dementia

Communication in advanced dementia is important to try to understand the person's experience and to be able to respond appropriately to their needs. It is also essential in order to provide social connection, honour personhood and share our common humanity.

Communication should be viewed broadly in advanced dementia, including language and other non-verbal approaches.

This means the sounds, gestures and movement of a person with advanced dementia can be viewed as attempts to communicate (Allan & Killick 2009). Adaptive interaction (Ellis & Zeedyk 2014) offers an approach to communication that responds to the movements and rhythms of people with advanced dementia. It provides a means of connection and interaction with a person who may otherwise be lost to their insular world.

Q16: What do you consider to be the key purpose(s) of communication in advanced dementia?

The key purpose of communication in advanced dementia is **making the social/human connection to allow the person to feel valued and cared for**. It is about supporting the person to make choices and influence their environment as much as possible using any retained skills and alternative forms of communication eg facial expression and body language.

It is about **enabling people living with advanced dementia to express their identity and make a contribution right to the end**. Part of this is responding to needs even if they are expressed in the most unconventional ways. Communication is to give human contact to that person whether it be touch, voice, music etc and let them know we are here. Connecting and interacting with others provides enjoyment and comfort within that moment. Another purpose is also to ensure distress is minimised for the person living with advanced dementia.

Q17: What approaches to communication would you recommend?

SLTs enable and support the person with dementia and their carers to deal with communication and swallowing difficulties. They:

- Assess a person's communication and their eating, drinking and swallowing abilities and needs
- Provide 1-1 or group therapy to help the person and their carers maintain the best possible communication
- Provide personalised eating and drinking plans to help the person and their family make the most of mealtimes
- Provide training and practical resources to help communication and / or eating and drinking to anyone living with, working for or providing a service to the person and their family.

Approaches to communication for people living with advanced dementia include:

- using pictures/photographs
- intensive interaction approaches (similar to adaptive interactions)
- communication through music, personal story books, objects of reference, through

touch and facial expression and gesture.

- Total Communication
- Talking mats

There is a significant body of evidence that demonstrates how effective these communications approaches and strategies are to people living with advanced dementia.

Environment

People with advanced dementia are likely to be living at home or in a care home. The rights based approach adopted by the Scottish National Dementia Strategy means that people should receive the same standard of care wherever they live. Environmental factors have a significant role in the quality of life of people living with advanced dementia.

Q18: What comments would you like to make on environmental factors and the importance of living conditions in advanced dementia?

The environment is significant to a person living with advanced dementia, and perhaps more subtle environmental changes are required for a person at this stage. **Training is a key issue** because care homes may know about the potential of environmental factors, there is less awareness amongst family members about how they could adapt their own home. In a care environment, however, there is greater risk that the individual is being made to fit a mould rather than a person-centred resource. The Stirling Dementia Centre has incorporated interesting environmental factors, but **there is definitely the potential to do more and increase awareness of how people living with advanced dementia respond to their environment.**

It is important to emphasise that the environmental factors are not simply about design or layout. It is about **the whole communication environment and understanding about how everything has the potential to communicate.** For example, noise, music, a curtain being opened or closed, a light being switched on or off could cause fear. As discussed in answers to other questions, prior knowledge about the person is crucial in this respect and getting the right kind of information from relatives and others. The person living with dementia must have as much **consistency** as possible, and understanding the whole communication environment is part of this person-centred approach so that communication can work better for the person in the advanced stage.

Mental and physical health care and wellbeing

The physical health of people with dementia needs increasing consideration as the condition progresses. Psychological symptoms continue to be prevalent in advanced dementia. Ensuring the medical condition is managed effectively is vital, as if neglected it can exacerbate the symptoms of dementia.

Q19: Anticipatory care planning and decision making

What comments would you like to make on anticipatory care planning and decision making?

Communication is key within care planning and decision-making. In working with people living with advanced dementia, it is clear from RCSLT members that using communication strategies, such as talking mats, help people who have lost formal capacity but still have capacity to participate in decision-making. All care and medical staff need to fully address

issues around capacity and consent, and there needs to be awareness of how SLT practitioners can support this process. The decision-making process must be centred on the person living with dementia, and a consideration of the communication skills of people involved in caring for that person, so that **appropriate communication strategies are used in care planning and decision-making**. Decisions must be well documented and the whole team needs to work together, communicating effectively with the person living with dementia as well as carers and staff.

In relation to SLT support and advanced dementia, decision makers must ensure SLT provision is suitable to meet this growing need, so that individual care planning includes SLT assessment and support.

Q20: Physical health care

What comments would you like to make on managing physical health care and wellbeing in advanced dementia?

In terms of both the physical health care and wellbeing of people living with dementia, it is vital that **eating, drinking and swallowing difficulties** are fully assessed and appropriate changes supported. As mentioned in previous answers, this is crucial to the intake and digestion of food to support physical health and also to reduce an anxiety, panic and stress and mealtimes (thereby improving wellbeing).

A related issue is properly managing a person's consent in physical care, and to support carers to understand **consent and legalities of intervention** is important. There are pathways that can be used, but healthcare workers need **training** about them.

Q21: Mental Health

What comments would you like to make on mental health and responding to psychological symptoms?

As already highlighted, communication difficulty can be exhausting for the person with dementia and affects their identity and relationships. Understandably, it can impact on the person's self-esteem and mood if their communication needs are not met. This can be because their own communication is poorly understood by those caring for them, leaving the person living with dementia feeling frustrated, anxious or depressed. It also can be because the people providing care are lacking in the appropriate communication skills and strategies for communicating with someone living with advanced dementia. Communication exclusion is a significant factor within mental health; as communication deteriorates, so can that person's mental health.

It is therefore vital that **the mental health needs of people with advanced dementia are not only given consideration, but also provided the right strategies and communication support throughout the care pathway**. A person who can clearly communicate their needs, and have those needs understood and met, and in turn be

appropriately communicated with, will have been given the opportunity to maintain and develop a stronger and healthier mental wellbeing.

Any approach to the mental health and psychological symptoms of a person living with dementia must include consideration of:

- the communication skills of the person
- appropriate communication strategies which should be used to support the person

Q22: Management of pain

Age is the greatest risk factor for both dementia and pain. Do you have any comments on the issue of recognising and responding to pain in advanced dementia?

The issue of recognising and responding to pain in advanced dementia is another example of where appropriate communication is vital. **If the person in pain has their communication needs met, they will be able to optimize ways of communicating the pain symptoms accurately and have that communication understood so the pain can be classified and appropriately treated by health care staff.** Again, if staff are well supported with appropriate communication strategies for communicating with the patient, they will likewise be able to find out accurate pain symptom information and consequently treat or manage the pain effectively for the patient.

Q23: Falls reduction

People who continue to be ambulatory in advanced dementia are at increased risk of falls. Do you have any comments on the issue of falls and falls reduction?

No comment.

Q24: Nutritional support

People with advanced dementia can develop swallowing difficulties. Do you have any comments to make on the issue of nutritional support?

Difficulties with eating, drinking and swallowing are a recognised challenge for people with dementia, particularly in the later stages. **Studies demonstrate the important role of SLTs in the assessment and management of dysphagia and in administering interventions and training staff.** Multidisciplinary consideration of eating, drinking and swallowing needs is an integral part of a comprehensive end of life approach (Royal College of Physicians

2010). Multi-disciplinary communication is especially vital to resolve dilemmas such as those who get nil by mouth who shouldn't be.

Nutritional support can be optimised where appropriate communication and dysphagia intervention has been provided by an SLT. Swallowing difficulties, however, is only one issue in the area of eating and drinking. Most people living with advanced dementia go through an array of difficulties with maintaining appropriate levels of nutrition. SLTs should be able to support and advise on these also.

Individuals with dysphagia should have access to appropriate levels of support in relation to diagnosis/instrumental assessment and treatment. **Carers** would also benefit from the right training to enable them to manage the individual's needs at home in relation to swallowing and drinking difficulties and optimising nutritional intake especially at the end stages of dementia. It is important, however, to also recognise the impact of other influences on nutritional intake such as challenging behaviour and, as mentioned above, this should be addressed accordingly.

Advanced directives are also important to remember in relation to swallowing difficulties, as well as family members understanding the risks of feeding and consequences of different decisions.

Q25: Under-treatment and over-treatment

People with advanced dementia are at risk of both over-treatment with burdensome, possibly non-beneficial interventions, and under-treatment of symptoms. Would you like to raise any issues either in relation to the risk of under-treatment and/or over-treatment?

The under and over treatment of people living with advanced dementia can result from ineffective communication. In the experience of RCSLT members, a concern is the over-treatment of challenging behaviour. People who work closely with those living with dementia must improve their response to challenging behaviours and understand these as a difficulty in communicating some unmet need. This would include becoming more proactive in referring these clients for SLT assessment rather than, or as well as, referring for mental health support. This can also prevent unnecessary hospital admissions especially given that a change of location can be really distressing for a person living with advanced dementia.

Advanced directives should be in place and communicated to the whole team in order to reduce treatment such as un-necessary PEG placements in individuals with advanced dementia.

Q26: Additional issues

Are there any additional issues do you feel need to be addressed in advanced dementia?

A few specific issues arose from discussion with RCSLT members:

Dementia team: Ensuring the whole team of people working with the person living with dementia is around at an earlier stage in order to help the process of communication, team-working and understanding the needs of the person when the dementia becomes advanced.

Eating, Drinking and Swallowing: A common issue arises regarding the need for a clear pathway about feeding when someone has a risky swallow. There is a need for more specific guidelines over who takes responsibility of that risk. SLTs can contribute to the decision over whether it is safe to feed the person, and understanding the wishes of the individual, but SLTs can't make the decision for non-oral feeding on their own. The decision has to be made by a multidisciplinary team.

Staffing levels and support: Improved staffing levels and increased support is required for families at home who care for people living with advanced dementia.

Q27: What responses would you propose to these issues?

Refer to answer to Q26.

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Next steps

The responses to this consultation will be taken forward into informing Alzheimer Scotland's Advanced Dementia Model to be published autumn 2015.

Please return your response before 28 February 2015:

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