

Summit: Living and dying well with dementia



Report on themes and key messages

Edinburgh Napier University

04 March 2011



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Contents

Introduction	07
Section 1: Key Messages	09
Section 2: Aim, Objectives and Structure of the Summit	11
Section 3: Themes	13
1. The role of palliative care	13
2. Advance care planning	13
3. Valuing and supporting families	16
4. Legal framework	17
5. Post-diagnostic support	18
6. Assessment and symptom management	19
7. Transitions	22
8. Resources	24
Appendix A: Programme	25
Appendix B: Definitions	26
• Advance/anticipatory care planning	26
• Dementia	26
• Palliative care	27
• Person centred dementia care	28
Appendix C: Case study	29
Appendix D: Evidence	32
Appendix E: Adults with Incapacity (Scotland) Act 2000: Principles	34

Introduction

Dementia is potentially a life-shortening illness and the experience of dementia varies widely. Some people with dementia have complex mental and/or physical health problems which may be life-threatening, and they may experience extreme physical and emotional distress as a result. For family members the impact of endeavouring to support the person they love while watching them endure such symptoms cannot be underestimated. All of this can present health and social care professionals with difficult ethical dilemmas and complex management problems.

Since the mid 1990s there has been a strong focus on the personhood of people with a dementia and providing care that is person-centred. This is reflected in the recent Scottish Government document, *Standards of Care for Dementia in Scotland*¹ which states that people with dementia 'have the right to be regarded as a unique individual and to be treated with dignity and respect', and that when this right is respected, people with dementia will:

'be valued and treated at all times as a person, with dignity and respect; be listened to, feel included and treated fairly; have individual needs, preferences and aspirations met; receive information and the necessary support to continue to participate in decisions which affect them now and in the future; and will not experience inhuman or degrading care or treatment'.

The person-centred approach outlined above and the palliative care approach both aim to be holistic, all-encompassing models of care, and the authors of this report believe that palliative care has a significant contribution to make to the person-centred care of people with dementia. There is a growing amount of evidence (see Appendix D) to support the view of the authors of this report, that general palliative care offers an approach and specialist palliative care offers specific expertise that can improve the lives of people with dementia and their families.

The literature (see Appendix D) points to a palliative care approach having benefits in areas such as: post diagnosis support and making plans for the future; treatment, care, and understanding the person's priorities; supporting and including family and carers through the experience; and proactively managing symptoms such as pain and distress. It can also provide a framework to support health and social care professionals to provide good care in the face of difficult ethical dilemmas and complex management problems.

Alzheimer Scotland Action on Dementia, Edinburgh Napier University and the Scottish Partnership for Palliative Care (SPPC) organised a Summit *Living and dying well with dementia*, which took place on 4 March 2011. The event was funded by NHS Education for Scotland (NES), Edinburgh Napier University and the SPPC. The Summit aimed to build on previous work by:

- Alzheimer Scotland which looked at improving understanding of a palliative care approach to care for people with dementia among a wide range of health and social care staff.
- NHS Lothian (funded by the Big Lottery) which had a dual focus on supporting family carers and the assessment and management of distress and pain for people with a dementia.

¹ Scottish Government (2011) *Standards of Care for Dementia in Scotland, Action to support the change programme, Scotland's National Dementia strategy*. Edinburgh: Scottish Government.



Structure of this report

Section 1

Outlines what the authors of the report believe are the key messages drawn from the day.

Section 2

Sets out the aim, objectives and structure of the Dementia Summit.

Section 3

Describes the themes that emerged during the Summit, through group discussions, speaker presentations or question and answer sessions. Some of these themes are further illustrated through direct quotes from participants. Definitions of dementia, palliative care and advance care planning are provided in appendices to the report, which also include more detail about the programme for the day and the case study on which group discussions were based.

Section 1: Key Messages

1. People have different understandings of what 'palliative care' is.

Palliative care specialists and Scottish Government policy agree that palliative care is not just about care in the last months, days and hours of a person's life, but about ensuring quality of life for both patients and families at every stage of the disease process from diagnosis onwards. (See Appendix A for full definitions of general and specialist palliative care.)

However, many healthcare professionals believe palliative care is provided only in the last few days of life and focuses on managing the process of dying.

2. People have different understandings of when palliative care is appropriate.

Palliative care specialists and Scottish Government policy agree that a palliative care approach should be used as appropriate alongside active disease management from an early stage in a disease process.

However, some health and social care professionals believe that palliative care is appropriate only after active treatment has stopped whilst acknowledging that identifying when active treatment should cease is difficult.

3. General palliative care offers an approach and specialist palliative care offers specific expertise that can improve the lives of people with dementia and their families, and which can support health and social care professionals to provide good care. This includes reducing the number of transfers experienced by a person with dementia, and maximising the use of limited resources.

- Advance/anticipatory care planning (ACP) is extremely important in the care of people with dementia, and ACP can and should include preferences for palliative and end of life care.
- Palliative care recognises the importance of family to a person, and care of the family is part of the palliative care approach.
- Palliative care specialists are experts in symptom control and the relief of physical distress such as pain, and can provide support in dealing with complex management problems.
- A palliative care approach addresses a person's social, emotional and spiritual, as well as physical, needs.
- Families and professionals caring for a person with dementia are likely to face ethical dilemmas, and palliative care specialists can help to provide support and advice in these situations.
- There is evidence to show that the quality of care of people with dementia in care homes is improved when the knowledge, skills and practice of staff are developed and supported by specialist palliative care staff.²

² Hockley J, Watson J, Oxenham D, Murray SA. The integrated implementation of two end-of life care tools in nursing care homes in the UK: an in-depth evaluation. *Palliative Medicine* 2010;24(8):828-838

Watson J, Hockley J, Murray S. Evaluating effectiveness of the GSFCH and LCP in Care Homes. *End of Life Care* 2010, Vol 4, No 3



4. *The Standards of Care for Dementia in Scotland state that ‘People with dementia will have access to a full range of palliative care services’. Misunderstandings relating to palliative care present a barrier to this.*

- There appears to be a fear among some health and social care professionals that indicating that a person may benefit from palliative care may result in a withdrawal of active treatment. In addition, many professionals are concerned that the connotations associated with the term ‘palliative care’ will unduly alarm people with dementia and their carers.
- Therefore, many health and social care professionals do not seek advice from palliative care professionals on ways to improve the care of people with dementia until it is very clear that the person is dying. Also, many health and social care professionals do not refer patients to specialist palliative care early on in the disease process.
- All of this means that many people with dementia and their families do not have access to specialist palliative care, and the family members and staff looking after people with dementia do not have access to the advice and expertise that would improve much of their general care.

Section 2: Aim, Objectives and Structure of the Summit

Aim and Objectives

The aim of the Summit was to explore the palliative care needs of people with dementia and the family members who care for them. It also explored the experiences of the family members of people with dementia. The objectives of the day were to:

- raise awareness of the issues relating to the palliative care of people with dementia and the family members who care for them
- identify challenges, find solutions and showcase examples of best practice
- capture discussion, debate and key messages from the Summit within a report for wider dissemination.

Structure of the Summit

50 participants with a strategic or academic role in health, social care or government were invited to take part in the Summit. The programme (*see Appendix A*) included expert speakers on a range of related topics, and delegates had the opportunity to share challenges, find solutions and showcase examples of best practice during discussion sessions. During the Summit a case study (*see Appendix C*) was presented and became the focus of inquiry for the discussion groups. The case study identified a range of experiences of a person with dementia and also the views of a family carer. Participants were invited to consider the case study in terms of the following aspects: clinical issues, systems of care, caring for the family and ethical considerations. The discussion groups were facilitated, scribed and recorded.



Section 3: Themes

THEME 1: The role of palliative care

Palliative care specialists and Scottish Government policy agree that a palliative care approach should be used as appropriate alongside active disease management from an early stage in a disease process. By this understanding, palliative care should be made available to people with dementia, where the slow trajectory of dementia may lead to a prolonged period of complex physical needs (months or years) and a palliative care approach could improve the quality of life during this phase of the illness.

'they are being very actively treated - quite often to the last few weeks of their lives - and that doesn't stop them having palliative care needs all the way through'

Delegates felt that people with dementia would often benefit from better pain management, anticipatory care planning and family support, all of which are integral parts of a palliative care approach. Specialist palliative care advice and support could also be helpful in helping staff and families through the difficult ethical decisions that may present themselves in the advanced stages of dementia. Specialist palliative care services can provide advice and support to professionals, families and the person with dementia if a decision is taken to withhold treatment.

'...There has been a big fear from palliative care services of exactly what [the] resource implications [might be]... how are we going to see all these patients, because of this 'floodgate' thing?... work [is needed] which is much more focused on consultation - giving advice in that situation, and education... you can affect 100s of patients with one day's education and that's how we need to develop services...'

However, there seems to be widespread confusion as to what 'palliative care' and a 'palliative care approach' is. Many of those involved in the care of people with dementia still associate palliative care with care at the very end of life, and fear that supporting a person to access palliative care will result in the withdrawal of active treatment. In addition to this, many professionals are concerned that the connotations associated with the term 'palliative care' will unduly alarm people. All of this prevents people with dementia from getting access to palliative care early on in the disease process.

'what I want for the person with dementia is the best possible quality of life, I want all those things you talked about, I want the best possible treatment, I want all of that. But if you come up to me and say 'palliative care'? I am going to run a mile.'

THEME 2: Advance care planning

'...my perception is that professionals have a problem - we don't like having these conversations because we are not comfortable with them... I think we are really missing a trick - they are difficult conversations and people might not want to go there, but I have also come across a lot of people who are absolutely relieved when they get that diagnosis - that explains it. There is that kind of moment - 'why, ok there is a reason for this, so [let's] see what I can do to plan...'

Good Practice

West Lothian Dementia Palliative Care Project

This project ran for three and a half years and was completed in August 2007. It had two phases: phase one involved conducting an assessment of the palliative care needs of people with a dementia and their family carers. The second phase was an action phase, where services participating in the project agreed a focus for change, implemented changes to practice and conducted evaluations. This second phase had a dual focus on supporting family carers, and the assessment and management of distress and pain for people with a dementia.

The conclusions from the project indicated that the following factors contributed positively to practice change: focusing on an agreed need of the service; participation of key stakeholders; action learning involving key representatives and the learning identified from individual case studies.

Care was positively enhanced by the implementation of established assessment tools for distress, pain and carer support, and these also improved healthcare professionals' understanding of the needs of people with dementia and their families. Due to the complex nature of assessing and managing distress and pain, formalised continuous team working and decision-making processes were key to achieving positive person centred outcomes.

Alzheimer Scotland: Beyond Barriers Project and Palliative Care Initiative

Beyond Barriers ran from 2006-2008, and involved the development of a palliative care and dementia course for care home staff to help them care for people in the later stages of dementia. The project consisted of a three-day joint education programme for relatives and staff, as well as further learning support sessions for staff to enable them to bring about a lasting change in practice. 100 dementia and palliative care champions were developed and 60 care homes took part.

The Palliative Care Initiative set out to build on the work of *Beyond Barriers*, developing the knowledge and understanding of a much wider audience, including health professionals. Training materials were developed and accredited, and a 'train the trainers' programme undertaken to facilitate the cascade training of a larger number of people. An evaluation of the programme by the University of the West of Scotland found that the initiative had been successful and had made a positive impact on practice. It identified that the training 'had a positive impact not just on the trainers, but has shown to have a positive effect on the attitudes and practices of a significant number of those staff, carers and volunteers exposed to the training'.

Advance care planning is key in palliative care, and promotes discussion in which individuals, their professional care providers and often those close to them, make decisions with respect to their future health or personal and practical aspects of care. A range of activities could be considered advance care planning, and in practical terms it is about adopting a 'thinking ahead' philosophy of care. Though not legally binding in Scotland, a professional would have to provide evidence for not following a person's expressed wishes.

There are several difficulties associated with advance care planning, including:

- Advance care planning cannot make provision for all the situations that may arise, and a person's needs or wishes may change as the dementia progresses.
- The challenges associated with a patient's lack of capacity to take decisions.
- Undertaking sensitive and careful advance care planning for everyone with dementia would require a significant amount of staff time, as well as staff having the high level of skill and confidence required to initiate these discussions. Advance care planning is also easier if staff have had time to establish a relationship with the individual with dementia.
- There are many aspects to advance care planning discussions, for example; granting a Power of Attorney, completing an advance directive, talking to family/ staff about concerns, values, understandings and preferences etc. However Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) can become the focus of discussions to the exclusion of issues that are perhaps more relevant to people with dementia.
- There is a lack of clarity as to whose responsibility it is to undertake ACP discussions with a person.

'it could have been somebody who was a vegetarian, that was just so little [a] part of them. And then you know at some point they are going to eat a steak. So do you actually stop them doing that if it is in their advanced statement that they want to remain a vegetarian but they are trying to take a bit [of] steak?'

Finding the right time for advance planning discussions takes sensitivity and can be difficult, and it must be acknowledged that some people may not wish to talk about future care needs. However, done properly it is beneficial to people in the long run:

- It gives people the opportunity to state their preferences for future care while they still have the capacity, increasing the chances that these preferences will be acted upon, and reducing stress and disagreements among family members about the correct course of action.
- It can elicit relevant knowledge from family members and give them the opportunity they desire to be involved in planning care.
- It allows an opportunity for calm and reasoned decision-making, making it less likely that when an urgent situation arises the wrong decision will be made.

'My family would have been very angry had I said - because we had agreed no resuscitation they would not have liked thatbut it was a decision we both took early on that if we reached this point we would both say what we wanted for the other'

ACP is extremely important in the care of people with dementia, and the Scottish Government document *Anticipatory Care Planning: Frequently Asked Questions*³ makes it clear that that ACP applies to people with dementia and that ACP can and should include preferences for palliative and end of life care.

Good Practice

For a person with dementia, there is a limited time when the person may have capacity to undertake advance care planning. Understanding that this brief window of opportunity needs to be used effectively, and that it is important to enable people with dementia to have a voice, Alzheimer Scotland, in conjunction with NHS Dumfries and Galloway, is working to produce appropriate paperwork and information to help people with dementia to make informed advance care planning decisions.

THEME 3: Valuing and supporting families

‘One of the biggest reasons why I got out of hospital nursing and into community [nursing] was because of the different model of being involved with the patient and the family and the community and a much wider look at... the whole person’

Family can be central to a person with dementia, just as a person with dementia is extremely important to their family. However, delegates felt that it was common for family members to be ignored or left out of important care decisions. People with dementia and their families should be able to express their needs, values and wishes, and staff should be able to hear and respond to these, recognising that an individual approach is required to suit the needs of each.

‘One of our staff has just won two awards for the care home and it was really around a more therapeutic liaison model with families, carers, care home staff. It’s really around that – therapy, good communication, the softer [elements] – sort of, ‘what would you like?’ ’

Palliative care recognises the importance of family to a person, and care of the family is part of the palliative care approach. Many specialist palliative care units and hospices provide accommodation so that carers can stay overnight. Forcing family members to leave a person with dementia alone in an unfamiliar environment (for example an acute hospital ward) can cause distress for all involved, worsen the symptoms and behaviour of the person with dementia, and cause behaviour management problems for staff.

‘we need to spend time with the [family] carers to allow them to provide some of the care’

³ The Scottish Government Health Delivery Directorate, Delivery and Support Team (2010) *Anticipatory Care Planning Frequently Asked Questions* Scottish Government (WWW) Available from: <http://www.scotland.gov.uk/Resource/Doc/309277/0097422.pdf>

The families of people with dementia need support to deal with the practical and emotional difficulties they face. Staff can play a major role in providing and facilitating support for families. Different families will have different needs, for example an advocate to champion the needs of the person with dementia, someone to talk to, bereavement risk assessment and follow-up support, or in-depth discussions from different professionals. Families are likely to need extra support when the person with dementia is moving to a new place of care, or to a new stage in their disease.

'It's a very lonely situation caring for someone with dementia, there is always someone there but you can't always talk about lots of things'

Where a family member is really struggling to deal with difficult behaviour, support to help them understand it all can help them to deal with feelings of helplessness, frustration and blame. Individuals with dementia and their families can find it beneficial to have ongoing support and information, such as that provided by Alzheimer Scotland's Dementia Advisors, signposting them to peer support networks or appropriate services. Small things can make a big difference to families, and not all support has to be time-consuming. Some of it is simply about attitude, and staff need to communicate and recognise that caring for the family is part of their role.

'if people just focus in on purely the numbers, the quality aspect isn't reflected upon'

The attitudes of the general public towards dementia are also important. People with dementia and their carers often stay at home because of fear or embarrassment at the reaction they are likely to receive from the people they meet. Delegates believed that negative reactions to people with dementia are largely due to lack of understanding, and there is a need for more openness within society regarding dementia and the difficulties it can present.

Delegates also expressed concern at the degree to which care and support for people with dementia is left to families and health and social care professionals, when communities and social networks potentially have a huge role to play. This issue is related to wider community engagement issues, and the need to build communities who are actively engaged in supporting members. This is an issue that is recognised within the national palliative and end of life care action plan *Living and Dying Well: Building on Progress*⁴, and national work is now underway to promote community involvement in death, dying and bereavement see:

<http://www.goodlifedeathgrief.org.uk>

'we [need to] get rid of the stigma in Scotland - if we don't talk about these things we won't move on'

THEME 4: Legal framework

a) Mental Health (Care and Treatment) (Scotland) Act 2003

One delegate shared her personal experience of her husband being made subject to a hospital based order under the above Act, and felt he was held in hospital and separated from her against the family's will and without any prior discussions or information.

⁴ The Scottish Government (2011) *Living and Dying Well: Building on Progress*. Edinburgh: Scottish Government.

Detaining people under this Act should be as a last resort to safeguard the welfare of the person and/ or those around them, and where detention in hospital is necessary families should be provided with information and support in relation to these decisions. Delegates shared their views that the Act is sometimes misunderstood or misused by staff.

b) The Human Rights Act 1998

Delegates gave several quite disturbing examples of staff justifying their provision of bad care to people with the claim that any alternative course of action would have been an infringement of that person's human rights. Ensuring staff's basic understanding of human rights legislation is therefore essential, both to ensure people's rights are upheld when they are at their most vulnerable, and also to support staff to be comfortable and deal properly with difficult decisions.

'I once went into a hospital ward, there was a chap who had Huntington's and this was late in the day, it was quite a few hours after his lunch, and he was still covered in the food from his lunch, and I went up to the nurse and said, 'obviously it has been some time will you be changing him?' '– no – it's his human rights he made himself messy, so he can stay messy'. That was a senior nurse in the NHS situation.'

c) Adults with Incapacity (Scotland) Act 2000

This Act makes provision for an individual to grant someone power of attorney relating to their personal welfare (a welfare attorney), should they later lose capacity to make these decisions themselves. It also allows for a relevant healthcare professional to certify someone as being incapable of making a decision about their own medical treatment (under section 47 of the Act). The Act sets out five overarching principles for its application: benefit; minimum intervention; take account of the wishes of the adult; consultation with relevant others; encourage the adult to exercise whatever skills he or she has. (See Appendix E for more detail.)

The law allows for the administration of emergency treatment without the individual's consent and without the completion of a section 47 form. However, this should only take place in a true emergency. Section 47 forms should be used in other situations where people are incapable of making their own medical decisions. This is because the completion of this form should ensure that all involved are adhering to the overarching principles of the Adults with Incapacity Act, and therefore are keeping the interests of the person at the centre of decision-making. The completion of a section 47 form is also the trigger for the decision-making responsibilities of the welfare power of attorney.

Families take on huge amounts of responsibility when they assume the role of welfare attorney but there is little accompanying support. Delegates felt that the relevant Code of Practice is not a user-friendly document, and that the existence of a welfare power of attorney is rarely well-documented within a person's notes. It can be additionally stressful and confusing if staff do not properly understand the role of power of attorney, and, for example, inappropriately involve a person who has been granted power of attorney in decisions for which they have no powers.

THEME 5: Post-diagnostic support

It is now widely accepted that receiving a diagnosis of dementia is essential if people are to receive the care and understanding they need throughout the course of their illness. However, receiving this diagnosis is likely to be upsetting for individuals and their families. People need information and support following diagnosis, to help them come to terms with the diagnosis,

inform their future decisions, and enable them to live life to the full. It is unclear whose responsibility it is to provide this kind of support. This is an issue that particularly affects people with vascular dementia, who often receive little or no post-diagnostic support until a crisis forces them back into 'the system'.

'we totally abandon particular people with vascular dementia because they have no need to be in any service, because they don't need a social worker, they don't need home care'

Good Practice

NHS Education Scotland has recently provided government funds to Alzheimer Scotland to develop and run a course on post diagnostic support. This is an in-depth course giving 30 staff with a remit to support people with dementia in the first year of diagnosis the knowledge and skills to provide the necessary support.

THEME 6: Assessment and symptom management

It is essential that people with dementia have their needs assessed at diagnosis and regularly thereafter, since poor assessment and treatment can result in an exacerbation of existing problems, leading to poor outcomes for people, such as untreated pain, unnecessary hospital admissions, and over-medication. From a palliative care perspective, it is important that there is assessment and regular review of a person's physical, psychosocial, spiritual and family's needs.

'... so much of the assumption [is] that the person with dementia is behaving in such a way because of the dementia, and there is not a flicker of a thought to be thinking about why it is they are behaving [in this way], as in 'do they have pain?' and so their pain is not managed because somehow there is an assumption that if they're not verbally articulating 'I have a sore hip', or whatever, then the person is not in pain...'

Case Study

In discussing the case study (see Appendix C) delegates questioned whether some of this individual's later problems could have been prevented by earlier intervention. It was felt that some of his behaviour and aggression may have been caused by undiagnosed discomfort or pain, and by an entirely predictable loss of control brought on by confusion and an unfamiliar environment. The case study illustrates how quickly troubles can multiply for people with dementia, and how easily a person can find themselves trapped inside a system that may be causing as many problems as it solves.

It can be difficult to assess whether or not a particular symptom is related to a person's dementia. For example, people with dementia are at increased risk of delirium, and this may be reversible given the correct treatment. However, delirium often goes un-diagnosed, being

mistaken for part of a person's underlying dementia. This is more likely to happen if professionals involved are unfamiliar with the person and therefore do not know what constitutes 'normal' behaviour for that individual. In this situation, family or friends who know the person well may be able to provide helpful information. Where a change in behaviour has been established, it is essential to try to establish *why* someone is behaving in a certain way, since changes in behaviour can also be a response to something else that is causing a concern, for example unrelieved pain.

The process of investigating a person's problem, for example by administering an anaesthetic or undertaking a scan, can increase the confusion of a person with dementia. This therefore raises questions about what is in the best interests of the person, and the circumstances under which these kinds of investigations should or should not be carried out. The involvement of specialist palliative care may be able to provide advice in these situations, and assist in making a person comfortable.

Good Practice

In NHS Dumfries & Galloway, specialist palliative care services often receive referrals from the acute sector, where people have been admitted surgically, medically or to orthopaedics with a condition that is not treatable because of comorbidities or advanced disease. For example, patients with severe pain from ischaemic limbs, or patients with fractured femurs who are unfit for theatre surgical intervention. Specialist palliative care can provide help with symptoms, assessment and care planning.

Where a person with dementia is on many drugs, it becomes difficult to tell what symptoms are due to the underlying illness, and what symptoms are side effects of the medication.

Case Study

Participants expressed concern at the quantity and variety of drugs being administered to the man described within the case study. It was suggested that it had become impossible to track the effects of all medication, and that drugs could have been adversely affecting the man's behaviour. It was felt that the focus of treatment was on controlling the man's behaviour rather than tackling its underlying causes.

Participants in the Summit were clear that it is essential to assess and treat a person's physical distress. However, it seemed that mental distress posed more of an ethical dilemma, and discussions brought to light what is likely to be a commonly felt unease among professionals about the practice of sedation. Palliative care specialists are quite clear that, having first tried other options, medication can be used to relieve mental distress. Though sedation may be a side effect of this medication it is not an aim of the treatment. The aim of the treatment is the relief of distress.

Good Practice

Care Home Ethics Committee

In a care home in Switzerland they formed an ethics group to talk about ethical issues and the care they were providing, for example talking about sexualised behaviour and how to address this in the care home and talk about this with the family.

a) Age

The current system means that people are assigned to different psychiatric services depending on whether they are over or under 65 years of age, and therefore people with dementia may receive different treatment depending on their age. Due to the higher incidence of dementia in older people, over-65 services have a much higher level of expertise in dementia than the under-65 services where dementia cases are relatively infrequent. This means that people with dementia who are under 65 may have fewer services available and staff with less experience of dementia.

When someone is under 65, it is unlikely that dementia will be immediately considered as an explanation for their behaviour/symptoms. It has also been suggested that the age of a person might influence ethical decisions relating to their treatment, for example whether or not to investigate or treat a condition.

b) Communication

Good communication between health and social care systems and professionals is key to the appropriate assessment and care of people with dementia, and break-downs in communication have a severe negative impact on care. For example:

- Professionals often don't ask families about the care of a person with dementia, yet families usually have a wealth of understanding, knowledge and experience relating to the preferences, needs and behaviour of a family member with dementia, and are usually keen to share this knowledge with anyone who can use it to improve the person's care.
- Relevant information about a person is often not shared between services, yet for the person with dementia, a lack of understanding of their symptoms and the reasons for their behaviour can make those symptoms and behaviour worse.

'If you don't have access to past and present medical, physical health and well-being and mental health history we are not really doing any service or justice to the patient.'

Good Practice

Personal profiles

NHS Borders is trying to get people to use 'This is me', a personal profile tool promoted by the Alzheimer's Society. The tool is designed to be simple and practical to complete, and someone going into hospital can give it to staff to help them understand their condition. It provides a 'snapshot' of the person with dementia, giving information about them as an individual, such as needs, preferences, likes, dislikes and interests. It is designed to enable staff to treat each person as an individual, thereby reducing distress for them and their carers and helping to prevent issues such as malnutrition and dehydration. Delegates were clear that personal profiles such as these can give staff background as to an individual's expected normal behaviour, helping them to establish if there has been a change, and if so, try to work out why.

c) Systems

It is important that the systems that are in place support rather than inhibit open communication with families. Sharing records and assessments between services improves assessment and symptom management, and as services move more towards electronic records it should become easier for records to be shared. The Emergency Care Summary (ECS) and electronic Palliative Care Summary (ePCS) allow certain pieces of information to be shared between services, and the Scottish Government is currently piloting a clinical portal initiative designed to allow all of a person's records to be accessed easily. However, improvements are still required, and certain systems present several barriers to effective communication, for example:

- The ECS does not currently include information about diagnosis or whether a person has a welfare power of attorney.
- Paper records may be held in different ways by different services.
- Psychiatric services retain notes, meaning that it is difficult for professionals working outwith that service to access these notes.
- Psychiatric notes are often long, complex and time-consuming to read.

THEME 7: Transitions

'every time you move somebody with dementia they actually go back... they deteriorate with each move'

As a person's health needs change, different services and departments become involved in their care. This can mean that a person with dementia is frequently moved from one service or department to another, and it is rarely clear who has responsibility for overseeing a person's care as they move through 'the system'.

Transfers such as this can be particularly traumatic for a person with dementia, who may not understand what is happening, and find change confusing. In addition, transitions make it difficult

for individuals and their families to build up relationships with staff, increasing stress and resulting in a loss of the rich information that can be gained by really getting to know a person. Information is often not shared between different departments or services, and the effects of this are compounded when several transfers take place in quick succession.

‘that is actually a very common scenario - that somebody does get into the system and once they are in the system they are on a conveyer belt and they are churned through.’

It is therefore important where possible to bring the care to the person rather than bringing the person to the care, to minimise the number of transitions for people with dementia, and to make necessary transitions as smooth as possible.

Good Practice

Nursing Homes Medical Practice

The Nursing Homes Medical Practice specialises in providing primary care services to nursing care homes in Glasgow, and currently covers approximately 2,650 people in 58 care homes. 54% of their patients have been diagnosed with dementia, and they look at diagnosis figures regularly, aware that they are still under-recording. 10% of their patients who are under 65 have dementia. GPs start to get to know patients before they are moved into a nursing home, liaising with hospitals. They use the Supportive and Palliative Action Register (SPAR) to help identify the likely needs of patients, support early identification of those who may need palliative care, and prioritise advance/anticipatory care planning, including anticipatory prescribing.

The work of the NHMP is based on the belief that accessibility to patients, carers and staff is vital, and relatives are informed of this approach so that they know what to expect. Though this practice deals with a higher than average incidence of many serious illnesses, recent analysis indicates that 80% of their patients die within the nursing home. This indicates that fewer individuals are being inappropriately admitted to hospital to die.

Environment

There are ways of making environments less confusing for people with dementia, for example by introducing good signage and painting rooms different colours so that people can more easily orientate themselves. One delegate explained that NHS Lanarkshire has used these techniques in all three of its acute hospitals.

Flagging System

NHS Borders operates a flagging system, so that a person coming from A&E has their dementia flagged up, and a protocol is followed which reduces the number of moves that person has to make and alerts those involved with that person outside of hospital.

Case Study: transitions

Delegates felt that the care pathway of the person within the case study lacked a sense of clarity or constructive management. Decisions were not consciously made about when to treat or not to treat, and the man was expected to live where it was practical rather than where was appropriate. It was felt that this resulted in an unhelpful and stressful journey of care that added to the man's problems.

THEME 8: Resources

This report covers the key themes that arose from the Summit, focusing on areas that relate specifically to dementia and/or palliative care. However, throughout the day, a general awareness was displayed of the resource constraints within which all aspects of health and social care in Scotland must work.

'time is not there and it is what you require'

Many of the shortcomings in the care for people with dementia are related to understanding of and respect for people with dementia. Much of this is dependent on organisational culture and the attitudes of staff. Nevertheless, ideal behaviours and solutions can be hard to achieve in an environment where staff are very busy and resources are limited. This was particularly emphasised with reference to acute settings, where it can be difficult for staff to provide appropriate attention to someone that has a known dementia, let alone those with undiagnosed dementia. It was suggested that ward staff should be able to flag up to their managers that they are caring for a number of people with dementia, and get appropriate help. Joint working between staff in acute settings and staff with particular expertise in dementia (or dementia champions) can help.

'it is about dignity and respect and the value of that individual in the process as much as it is about the lack of resources'

Much of the responsibility for the ongoing care of people with dementia falls to staff within care homes or NHS continuing care services. Scottish Care is working with care homes in Scotland towards care homes being perceived as positive options for individuals.

'The health service is very reactive now – you don't actually think ahead and plan the bigger picture. I think that is down to resources.'

A lack of understanding of dementia among staff leads to bad outcomes and experiences for the person and their family. For example, many staff have difficulties dealing with the complexities arising from dementia when there are both physical and mental aspects to the condition, there is a tendency for every specialty to focus only on their area of expertise, and persuasion and coercion are often seen as the only approach to 'managing behaviour'. Exemplary handling of the complex issues that arise from working with people with dementia and their families takes a high level of skill, sensitivity and understanding from staff. Giving staff the training and time they require to achieve this level of skill can be resource intensive.

Appendix A: Programme

Summit: Living and Dying Well with Dementia Edinburgh Napier University, 4 March 2011

9.00	Registration and coffee	
9.30	Welcome and introduction	Chair: Mark Hazelwood Director Scottish Partnership for Palliative Care
9.40	End of life and dementia: photographs by Cathy Greenblat internationally respected sociologist and photographer	Introduced by Jenny Henderson Development Manager, Alzheimer Scotland
9.55	A conversation about caring for a person with dementia	The Duchess of Hamilton and Barbara Sharp Practice Development Manager, Alzheimer Scotland
10.15	Alzheimer Scotland's Dementia Palliative Care Initiative and launch of report	Jenny Henderson Development Manager, Alzheimer Scotland
10.30	An acute sector perspective on palliative care and dementia	Professor Emma Reynish Consultant Physician, NHS Fife
10.45	Questions and answers	Panel of presenters from the morning session
11.00	Coffee	
11.20	Session 2 introduction	Chair: Henry Simmons Chief Executive, Alzheimer Scotland
11.25	Presentation of case study	
11.30	The challenges of the case study	Peter Lerpiniere Dementia Nurse Specialist, Alzheimer Scotland and NHS Borders
11.45	A care home sector perspective on palliative care and dementia	Ranald Mair Chief Executive, Scottish Care
12.00	A GP perspective of palliative care and dementia	Dr Jean Hannah Clinical Director of Nursing Homes, Greater Glasgow and Clyde
12.15	Questions and answers	Panel of presenters from session 2
12.25	Discussion groups	
13.10	Lunch	
13.40	Session 3	Chair: Dr David Oxenham Medical Director Marie Curie Hospice, Edinburgh
13.45	Dementia Palliative Care Needs Assessment*	Dr Stephen Smith Lead Nurse Edinburgh Napier University and NHS Lothian
14.00	A perspective of palliative care and dementia	Dr Lindsay Martin Specialist Palliative Care Consultant, NHS Dumfries and Galloway
14.15	A perspective of palliative care and dementia	Dr Donny Lyons Director Mental Welfare Commission
14.30	Questions and answers	Panel of presenters from session 3
14.40	Discussion Groups	
15.40	Identifying key messages from discussion groups	
15.50	Summing up and evaluations	
16.00	Close of day	

*This session was omitted due to sickness absence

Appendix B: Definitions

Advance/anticipatory care planning

Anticipatory and advance care planning (ACP), in practical terms, are both about adopting a 'thinking ahead' philosophy of care that allows practitioners and their teams to work with people and those close to them to set and achieve common goals that will ensure the right thing is being done at the right time by the right person(s) with the right outcome. Advance care planning is the term most commonly referred to in end of life care, although it does incorporate the writing of wills or 'living wills' now known as advance directives or advance decisions which can be done by the well person early on in life to plan for what may happen at the end of life. Anticipatory care planning is more commonly applied to support those living with a long term condition to plan for an expected change in health or social status. It also incorporates health improvement and staying well. Completion of a common document called an anticipatory care plan is suggested for both long-term conditions and in palliative care.

Definition taken from the Scottish Government Health Delivery Directorate, Delivery and Support Team (2010) *Anticipatory Care Planning Frequently Asked Questions* Scottish Government (WWW) Available from:

<http://www.scotland.gov.uk/Resource/Doc/309277/0097422.pdf>

Dementia

Dementia is the progressive loss of the powers of the brain. There are many kinds of dementia but the most common is Alzheimer's disease. In Scotland in 2012, there are approximately 84,000 people with dementia. Around 3,000 of these people are under the age of 65. The numbers of people with dementia in Scotland are expected to double in the next 25 years. It is most common in older people but can affect people in their 40s or 50s or even younger. Every person with dementia is different. How their illness affects them depends on which areas of their brain are most damaged.

One of the most common symptoms of dementia is memory loss.

People with dementia may lose their sense of time, losing awareness of which day it is or of the time of day. They may lose track of where they are, and get lost even in a familiar place. They may fail to recognise people they know well. Their ability to think, to reason and to calculate can all be damaged. They may make odd decisions and find it hard to solve problems. Handling money may become difficult as they find it harder to work out their change or lose their sense of the value of money.

Verbal communication can be affected and people with dementia rely far more on non-verbal communication. Their attempts to communicate are often expressed through behaviour. Gradually, over a period of years, most functions of the brain will be affected. Eventually, people with dementia will probably need help with even simple daily activities, such as dressing, eating or going to the toilet.

Palliative care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patient's and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness, and is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

World Health Organization Definition of Palliative Care

<http://www.who.int/cancer/palliative/definition/en/>

General palliative care is an integral part of the routine care delivered by all health and social care professionals to those living with a progressive and incurable disease, whether at home, in a care home, or in hospital.

General palliative care is care that is based on the understanding and practice of palliative care principles. These include:

- a focus on quality of life which includes good symptom control
- a whole person approach which takes into account the person's past life experience and current situation
- care which encompasses both the person with the life-threatening illness and those that matter to that person, respect for patient autonomy and choice
- emphasis on open and sensitive communication.

Specialist palliative care is based on the same principles of palliative care outlined above, but can help people with more complex palliative care needs. Specialist palliative care is provided by specially trained multi-professional specialist palliative care teams and can be accessed in any care setting.

Person centred dementia care

Definition taken from: Bellchambers, H. and Penning (2007), C. Person Centered Care: A philosophy of care and management of carers. *Contemporary Nurse* Volume 26. Issue 2 page 196 -198.

The works of both Kitwood and Brooker build on the 1950s research of the psychotherapist Carl R. Rogers, who developed the person-centred approach as a method of facilitating psychological growth (Natiello 2001).

Rogers' approach was a radical departure from the authoritarian assumption that professional experts could and should help by solving others' problems for them, with the expectation that clients would then somehow be better able to solve their own problems (Rogers 1977).

Tom Kitwood applied this approach to clients experiencing dementia and developed responses that contrasted starkly with the more 'technical' versions determined by the medical model at that time. Kitwood believed that a focus on dementia from the perspective of an organic mental disorder ignored the larger human issues and he therefore strove to create a new paradigmatic view of dementia in which 'the person comes first' (Kitwood 1997: 2). His research sought to provide a better understanding of the different ways in which personhood (that is the way in which one person views the status of another) was undermined for those people who were living with a diagnosis of dementia.

One of the common theories upon which Kitwood built his research protocols was the assumption that all human beings have the five following fundamental psychological needs:

- **Comfort**, the provision of warmth and strength
- **Attachment**, the forming of specific bonds or attachments
- **Inclusion**, being part of a group
- **Occupation**, being involved in the process of life
- **Identity**, having a sense and feeling of who one is (Kitwood 1997: 81).

Appendix C: Case study

Background information (Some information has been changed to preserve the anonymity of the individuals concerned)

Patient X was a keen cyclist and hill-walker, a big strong man and very fit. He lived with his wife and son. On the diagnosis of Alzheimer's he was prescribed *Aricept* and referred to the memory clinic link-worker who over the following years provided support, advice, education and friendship.

One of the difficulties patient X had was that he was suspicious of his family and this led to tensions and physical violence with a close family member. With help this was managed and personalised support was provided. When it was no longer possible for him to go out he had a care package within his home.

He developed a urinary tract infection and was admitted to hospital where he spent twelve weeks. During this time he lost confidence and on return home he was insecure and did not cope. He developed a further urinary tract infection and was re-admitted to hospital. He was discharged to a residential care setting. The staff did their best, but struggled to cope with him. He became frustrated and exhibited aggressive behaviour. This led to admission to an acute psychiatric assessment unit where he was treated with a variety of antipsychotic and sedative medication. His behaviour became more difficult and required one to one nursing. He was placed on a short-term detention order under the Mental Health (Care and Treatment) (Scotland) Act 2003 and this was later extended to a compulsory treatment order.

Notes from medical records

He was first diagnosed with dementia in his fifties, when he was both working and driving – very poor memory and this caused him considerable distress. At no point in acute care notes is there any mention of any discussion with this young man about advance care planning.

Psychiatric notes not seen.

5 April 2009

60 year old man. Diagnosis of pulmonary embolus.

Was at that time in psychiatric hospital with increasing aggression. Noted to collapse suddenly with dyspnoea and hypotension. Transferred to acute hospital where he required general anaesthetic for CTPA scan to confirm pulmonary embolus. Treated under Adults with Incapacity (Scotland) Act. Medical notes talk about several months of active ongoing treatment. Referred back to psychiatric hospital.

1 June – 7 June 2009

Transferred from psychiatric hospital (short-term detention followed by a hospital-based compulsory treatment order granted under the Mental Health (Care and Treatment) (Scotland) Act 2003) as the criteria of the Act were met. Fully mobile, but developed sudden onset of chest pain was felt that pain was a result of previous pulmonary embolus. Whilst in the acute hospital, had a member of the psychiatric team in attendance. Fully able to speak in long

sentences and did not appear distressed, but had obviously very poor short-term memory. Continued on daily low-molecular weight Heparin injections and returned to the psychiatric hospital. Medication at that time prn *Lorazepam*, two doses of 1gm of *Paracetamol*, *Quetiapine*, *Galantamine*, *Citalopram*.

12 to 13 June 2009

Hypotension and bradychardia. Transferred to acute hospital. Atenolol discontinued. During this admission, noted to be aggressive, with a note that often he had three people in attendance with him at the psychiatric hospital. Notes say didn't settle with persuasion, dimming lights, etc. Next note says needed up to six people to hold him back from lashing-out and he was given intramuscular *Lorazepam* and *Haloperidol*. Discharged back to the psychiatric hospital the day after admission with 'no plans to follow up patient X'.

24 August 2009

Referral to the Specialist Palliative Care team, when he was seen in the psychiatric hospital and was noted to be very agitated and restless. Note says that he had changed from a calm man to progressive and extreme agitation, when *Citalopram* was withdrawn. The cause of his agitation and restlessness was uncertain, and because he was non-compliant with oral medication, it was agreed to use *Fentanyl* patches. Three days later he was much more settled, but obviously very much less well and he was transferred to the palliative care unit, requiring increasing medication for agitation and dyspnoea.

The doctor's note states that he was profoundly agitated and distressed, although the cause impossible to ascertain. Staff frequently having to restrain him, both physically and with medication. Staff had 'produced an excellent time-line of his increasing agitation and distress during this admission'. I have noted discussion with patient X. Staff and family agree to relieve distress and initially commenced on *Fentanyl* patch. Initially settled, but then became increasingly agitated and was transferred to the palliative care unit. Focus of care on relief of distress, even if this required heavy sedation.

Initially, after transfer, staff in the unit were supported by staff from the psychiatric hospital. It became apparent this was unnecessary. Died very peacefully four days after transfer, with his family present. Family said that they had felt able to sit with him and remember him as being the loving father and husband that he had been.

Carer's account: 24 February 2011

It's hard to think of my Dad before he was ill but I would describe him as confident, supporting and successful. When he became ill all that changed, we found it a very sad, tiring and challenging time.

When he was in the care home it was very sad it was not the right place for him, but where else could he go? He could not stay at home. He was much more aware than the others in the home. There was no one for him to talk to. He tried to make sense of who he was and asked me to confirm his name ... he repeated it over and over again. He needed lots of reassurance. It was hard to deal with all the aggression – it was not my Dad.

When he was in the acute psychiatric hospital I was always frightened of how he would be ... I was never frightened of him. There was one occasion when he was so distressed the staff advised us not to see him. I found this really difficult I just wondered what was happening ... I was afraid for him, on good days he was afraid for himself but there were times when he did not know what was happening and needed reassurance.

The staff were more able to support him in the psychiatric hospital than other places. In A&E they didn't understand he could not answer their questions and on the acute hospital ward unless we were there he would not necessarily get his meals – they were placed in front of him but he was not helped to eat them.

The palliative care unit was a huge contrast it was by far the nicest place he was in, it was peaceful and we were allowed to visit any time. The move to the palliative care unit and the care he received there was the right thing to do ...

All staff we encountered were very nice and I have a huge respect for them ... they all do a great job.

What regrets do I have?

This all happened six months ago and I am still quite numb.

I wished I went to see him more ... but it was too hard. I went on a week's self help course to try to help me come to terms with what was happening so I could visit more ... but it didn't help.

I found it very difficult that I couldn't have a proper relationship with him ... you don't think at my age that you will have to look after your Dad ... he should have still been looking after me.

What would I want to tell people who are able to influence care and services?

- These people are still human beings and deserve a right to as good a life as possible
- There needs to be the right provision – my Dad needed to be somewhere where he could relate to people and make friends
- The support from the palliative care team was important
- There should be a better understanding of the illness
- People with dementia should not be moved around as much.

Appendix D: Evidence

Evidence that palliative care offers an approach and specific expertise that can improve the lives of people with dementia and their families, and which can support health and social care professionals to provide good care in the face of these difficult ethical dilemmas and complex management problems:

Alzheimer Europe. End of life care for people with dementia. 2008

Birch, D. and Draper, J. (2008) A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia. *Journal of Clinical Nursing* 17 1144-1163

Care Commission (2008). *Better care every step of the way: report on the quality of palliative and end of life care in care homes for adults and older people*. Dundee: Care Commission.

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Evans, B. (2002) Improving palliative care in the nursing home: from a dementia perspective. *Journal of Hospice and Palliative Nursing* 4 2 91-99

Froggatt, K. and Payne, S. (2006) A survey of end of life care in care homes: issues of definition and practice. *Health and Social Care in the Community* 14 4 341-348

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Kelly, F. and Innes, A. (2010) *End of life care for people with dementia: a best practice guide*. Dementia Services Development Centre, University of Stirling.

Murray, S.A., Kendall, M., Boyd, K. and Sheikh, A. (2005) Illness trajectories and palliative care *British Medical Journal* 330 1007-1011

National Council for Hospice and Specialist Palliative Care Services and the Scottish Partnership Agency for Palliative and Cancer Care (2000). *Positive partnerships- palliative care for adults with severe mental health problems*. London: National Council for Hospice and Specialist palliative care services.

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Sampson, E., Ritchie, C., Lia, R., Raven, P. and Blanchard, M. (2006) A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. *International Psychogeriatrics* 17 31-40

Shega, J., Levin, A., Hougham, G., Cox-Haley, D., Luchins, D., Hanrahan, P., Stocking, C. and Sachs, G. (2003) Palliative Excellence in Alzheimer Care Efforts (PEACE) Palliative Excellence in Alzheimer Care Efforts :A program description *Journal of Palliative Medicine* 6 2 315-320

Small, N., Froggatt, K. and Downs, M. (2007) *Living and Dying with Dementia: Dialogues about Palliative Care* Oxford: Oxford University Press

Volicer, L. (2001) Management of severe Alzheimer's disease and end of life issues. *Clinics in Geriatric Medicine* 17 2 377-391

Appendix E: Adults with Incapacity (Scotland) Act 2000 - Principles

Principle 1 - benefit

There shall be no intervention in the affairs of an adult unless the person responsible for authorising or effecting the intervention is satisfied that the intervention will benefit the adult and that such benefit cannot be reasonably achieved without the intervention.

Principle 2 - least restrictive option

Where it is determined that an intervention in the affairs of an adult under or in pursuance of the 2000 Act is to be made, such intervention shall be the least restrictive option in relation to the freedom of the adult, consistent with the purpose of the intervention.

Principle 3 - take account of the wishes of the adult

In determining if an intervention is to be made, and, if so, what intervention is to be made, account shall be taken of the present and past wishes and feelings of the adult so far as they can be ascertained by any means of communication, whether human or by mechanical aid (whether of an interpretative nature or otherwise) appropriate to the adult. Before concluding that someone is totally unable to communicate and therefore lacks capacity, strenuous efforts must be made to assist and facilitate communication - using whatever method is appropriate to the needs of the individual, including advice and assistance from a speech and language therapist. *It is important to note that it is compulsory to take account of the present and past wishes and feelings of the adult if these can be ascertained by any means possible.*

Principle 4 - consultation with relevant others

In determining if an intervention is to be made, and, if so, what intervention is to be made, account shall be taken of the views of:

- the nearest relative and primary carer of the adult;
 - the named person;
 - any guardian, continuing attorney or welfare attorney of the adult who has powers relating to the proposed intervention;
 - any person whom the sheriff has directed should be consulted; and
 - any other person appearing to the person responsible for authorising or effecting the intervention to have an interest in the welfare of the adult or in the proposed intervention, where these views have been made known to the person responsible
- in so far as it is reasonable and practicable to do so.

Principle 5 - encourage the person to exercise whatever skills he/she has; and the development of new skills

Any guardian, continuing attorney, welfare attorney or manager of an establishment exercising functions under this Act shall, in so far as it is reasonable or practicable to do so, encourage the person to exercise whatever skills he/she has concerning property, financial affairs or personal welfare as the case may be, and to develop new such skills. This would also be normal good practice for others providing support to the person.

Excerpt from: *Adults with Incapacity (Scotland) Act 2000: Code of Practice: For Local Authorities Exercising Functions under the 2000 Act*. Accessed in June 2011 from:

<http://www.scotland.gov.uk/Publications/2008/03/20114619/2>

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