

A report from a
one day conference on
11th February 2003
to examine and reflect
on the issues of
palliative care and its
provision for people
with learning disabilities

PALLIATIVE CARE AND PEOPLE WITH LEARNING DISABILITIES

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ISBN 1 899751 23 8
First published July 2003



Acknowledgements

Common Knowledge, the Scottish Partnership for Palliative Care and St Columba's Hospice wish to thank the following people:

Donald Macaskill, Scottish Human Services Trust; Patricia Wallace, Scottish Partnership for Palliative Care; Fiona Cathcart, St Columba's Hospice; the staff at Common Knowledge who developed the conference and organised the day; the speakers and workshop contributors who presented their knowledge and experience; the conference participants who shared their experience.

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Most of the text on pages 46 - 49 and in appendix 4 has been reproduced from an unpublished article prepared by Dr Beattie in June 2002.

Biographical details of all the contributors are given in Appendix 1.

The production of this report has been assisted by funding made available from the Scottish Executive through its Patient Focus Public Involvement programme.

Contents

1	Introduction	7
	PART ONE - PAINTING THE PICTURE	13
2	Overview of the health needs of people with learning disabilities in Scotland	15
3	Barriers in meeting the health and palliative care needs of people with learning disabilities	18
4	Challenges for practice and models for overcoming barriers	23
5	What is the picture?	29
	PART TWO - FINDING THE WORDS	31
6	Finding the words - pain assessment and control	33
7	Death, dying, loss and grief	38
8	Control, consent and the Adults with Incapacity (Scotland) Act 2000	46
	PART THREE - TAKING ACTION: WHERE TO FROM HERE?	51
9	Taking stock	53
10	Taking action - suggestions for improving services	57
11	Concluding comments	62
	APPENDICES	
	1 Speakers' biographical details	63
	2 References and further reading	66
	3 Resources and contacts	71
	4 Adults with Incapacity (Scotland) Act 2000	77

1 Introduction

This event was the first major conference in Scotland to provide a platform for discussion of the palliative care needs of people with learning disabilities. Over 120 people attended it. Delegates with expertise and interest in palliative care joined delegates with expertise and interest in supporting people with learning disabilities¹ to discuss their palliative care needs and the response of services.

Participants came from all over Scotland; from health and social care settings. They came to hear speakers of national and international repute reflect on and share experience and knowledge and to develop an agenda for improvement and change.

The conference was organised by Common Knowledge, the Scottish Partnership for Palliative Care and St Columba's Hospice. Dr Donald Macaskill, Head of Training and Learning with Scottish Human Services Trust, chaired the day.

- Common Knowledge is a learning partnership which has been developed to promote inclusion for people with learning disabilities in Glasgow.
- The Scottish Partnership for Palliative Care works to ensure that people in Scotland who have progressive life threatening conditions, such as cancer, motor neurone disease or advanced heart failure, receive good palliative care.
- St Columba's Hospice is an independent Specialist Palliative Care Unit, recognised as a charity. It contracts with NHS Lothian and it accepts patients from the Lothian area and further afield. It is committed to the care of patients with active, progressive, far-advanced illness and to the support of their relatives. Its clinical services include an in-patient unit, community palliative care services and a day hospice.

You will find contact details for these organisations in Appendix 3 to this report.

1.1 Why we are producing a conference report

It was evident at the conference that participants and presenters valued being able to share experience and to network. It was also clear that there have been few occasions in the past where people from different professional

¹We acknowledge the difficulty of language and labels and that many people prefer to use the term 'learning difficulties'. However we are using the term 'learning disabilities' in this report because that is the term used by the Scottish Executive.

backgrounds had come together and broken down barriers around this important topic. Palliative care experts sometimes felt inadequate and ill prepared when faced with the particular needs of someone with learning disabilities. Similarly many people with knowledge and expertise of living and working with people with learning disabilities knew little about palliative care and supporting someone at this stage of their life. It is important therefore that the information given, and the issues raised, should be disseminated to a much wider number of people than can attend a conference.

In his Chairman's introductory remarks, Donald Macaskill expressed the best wishes for a successful conference from Frank McAveety, Deputy Minister for Health and Community Care. Participants and presenters were eager that this first event in Scotland should become a springboard for national recognition of the issues raised at the conference. The developing agenda from this conference should set some benchmarks for future monitoring of the quality of palliative care services received by people with learning disabilities, their families and carers.

1.2 Who should read this report and why?

- People who were present at the conference will have a summary of the conference presentations and themes of the workshops and find access to additional materials and ideas that may be useful in their day to day work.
- People in the Scottish Executive, NHS Boards and Trusts, palliative care partnerships and Health Councils will recognise the importance of this subject and the implications for policy and practice change.
- People who work with and provide services for people with learning disabilities will also recognise the growing importance of this issue and will want to take action to deliver responsive and sensitive services.
- This is an area which has received little attention or profile within health or social services. People who provide services and people who use them will be interested in the current position and opportunities for becoming involved in developing existing and new services.

1.3 Structure of the report

The report is organised in 3 main parts, each with subsections.

Part One Painting the picture

- Overview of the health needs of people with learning disabilities.
- Barriers in meeting the health and palliative care needs of people with learning disabilities.
- Challenges for practice and models for overcoming barriers.

Part Two Finding the words

- Finding the words - pain assessment and symptom control.
- Death, dying, loss and grief.
- Control, consent and the Adults with Incapacity Act (Scotland) 2000.

Part Three Taking action

- Taking stock.
- Taking action - suggestions for improving palliative care services for people with learning disabilities?

The content of Part One is taken from presentations given at the conference by Michael Brown, Linda McEnhill and Dr Claud Regnard supplemented by discussions at the workshops. Part Two has been derived from presentations by Claud Regnard and workshop presentations and discussions led by Jo Hockley, Dr John Swinton, Dr Rosaleen Beattie and Belinda Paris. Part Three presents Fiona Cathcart's overview in the final presentation at the conference. It also draws together action points raised by speakers and participants throughout the day to move forward in addressing the palliative care needs of people with learning disabilities.

At the end of the report you will find biographical details of the speakers and facilitators, a reading list of materials on this subject, and a list of useful organisations and web-sites.

1.4 What is palliative care?

There are different definitions of palliative care and understanding of the term may depend on an individual's experience of palliative care as a professional, as a patient or as a relative.

The World Health Organisation says:

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...

It details nine elements of palliative care.

1. It provides relief from pain and other distressing symptoms.
2. It affirms life and regards dying as a normal process.
3. It intends neither to hasten nor postpone death.
4. It integrates the psychological and spiritual aspects of patients' care.
5. It offers a support system to help patients live as actively as possible until death.
6. It offers a support system to help the family cope during the patient's illness and in their own bereavement.
7. It uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.
8. It will enhance quality of life and may also positively influence the course of illness.
9. It is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiotherapy and includes those investigations needed to better understand and manage distressing clinical complications.

In Our National Health: A plan for action, a plan for change, the Scottish Executive Health Department defines and supports palliative care and also makes a clear commitment to addressing the needs of excluded groups.

Palliative care deals with the total care needs of people including relief from pain and other distressing systems, and with social and spiritual issues... we will ensure that effective palliative care services are supported.
(Our National Health, page 74)

These definitions are reflected in the information and discussion which follow in the rest of this report.

Part One
Painting The Picture

2 Overview of the health needs of people with learning disabilities in Scotland

2.1

Over the last ten years, and continuing until 2005, we have welcomed and will welcome some 20 - 30,000 adults with learning disabilities into our communities from long stay hospitals. Individuals resettling in ordinary communities, and those who have always lived there, are people with health needs who need to access health services.

Michael Brown set the context for the conference and this report with a comprehensive tour of facts, figures, issues and challenges concerning the health of people with learning disabilities. He set these in the Scottish policy context for health and community care and against a background of historically poor provision and inadequate access to services for people with learning disabilities. This gave a framework for later presentations by Linda McEnhill, Chief Executive of the National Network for the Palliative Care of People with Learning Disabilities and Dr Claud Regnard, Palliative Care Consultant, Northgate and Prudhoe NHS Trust.

2.2

People with learning disabilities are people first. They are included in and affected by the general state of Scotland's health - or ill health. They have health needs like everybody else. Often they have poorer health, yet their health needs have not been adequately met.

2.3

Michael presented a picture of poor health, an increasing and ageing population of people with learning disabilities and unmet health needs. These are the drivers for the development of a range of policy initiatives since the Scottish Parliament came into being.

- Health in Scotland is poorer than in the rest of Europe.
- There are at least 120,000 people with learning disabilities in Scotland, representing 2-3% of the population. The population of Scotland is projected to decrease and the number of people with learning disabilities is projected to increase, at a rate of approximately 1.1% per annum. Thus the proportion of the population with learning disabilities will increase.
- The population is ageing. This applies to the people of Scotland and to people with learning disabilities.
- People with learning disabilities who have complex needs are living longer. In 1939, the mean age of death for people with

Down's syndrome was 12 years; now 80% of people with Down's syndrome can be expected to live to over 50 years.

- We have very limited data on the needs of people with learning disabilities across the course of their lives in order to inform service planning.
- There is evidence that historically the health needs of people with learning disabilities have not been addressed, whether they lived in long stay hospitals or in the community.

This is the background to the conference's focus on the palliative care needs of people with learning disabilities as part of their wider health needs.

2.4

Michael Brown outlined key policy documents, supporting the need for action to address health inequalities and to promote inclusion for people with learning disabilities. These include:

- [Our National Health: A plan for action, a plan for change.](#)
- [Caring for Scotland.](#)
- [The Same as You? A review of services for people with learning disabilities.](#)
- [Nursing for Health: A national review.](#)
- [Promoting Health, Supporting Inclusion.](#)

You can find further details on all these publications, and where to find them, in Appendix 2.

2.5

[The Same as You? A review of services for people with learning disabilities \(2000\)](#) sets out the Scottish Executive's ten-year strategy for improving services, especially in social and health care. It recognised that services are there to support people in their daily lives and that in Scotland the pattern of these services is not as advanced as in many countries in Europe. It resulted in 29 recommendations for actions that would improve the quality of life for people with learning disabilities. These are being taken forward by 'The same as you' National Implementation Group. This is led by the Scottish Executive and includes representatives from health, social work and housing agencies and users and carers.

Michael Brown highlighted a few of the recommendations which have or could have an impact on palliative care services.

- NHS Boards should have plans for closing all remaining long stay hospitals by 2005.
- NHS Boards and Local Authorities should agree to appoint local area co-ordinators for learning disabilities. This should mean there is a local resource for people with learning disabilities, their families, carers and professionals. The box below explains more about local area co-ordination.

What is local area co-ordination?

Local Area Co-ordination is a concept that was first developed by the Disability Services Commission in Western Australia. Local area co-ordinators can be from any profession, but in Scotland are likely to be based in local health care co-operatives (LHCCs).

They operate from local offices and work within the community to assist people with disabilities and their families and carers to plan, select and receive the support and services they need. They get to know people personally, building relationships, supporting networks and making connections within the community. They are service co-ordinators rather than service providers, helping people to make plans and decisions about the services they want and helping them to choose who will provide these. They have a budget to provide funding directly to the people who use services and they try to get hold of new funding where there are gaps in services.

3 Barriers in meeting the health and palliative care needs of people with learning disabilities

3.1

People with learning disabilities have the same everyday health needs as anyone else and need to access the same services - registration with a GP, immunisation, screening. There may be health needs that are a result of a learning disability condition or closely allied with it. For example people who have Down's syndrome are more likely to have allied heart conditions. Some people may have multiple and complex needs.

Against the background of health needs painted by Michael Brown, Linda McEnhill spoke about the barriers for people with learning disabilities and those who care for them when they need preventative and palliative health care. She also spoke about the disease profile of people with learning disabilities with particular reference to cancer before going on to consider the challenges for practice. Dr Claud Regnard also outlined some facts about the changing health needs of people with learning disabilities.

3.2 Diagnostic approaches

Michael Brown said that care is needed to ensure that a label of 'learning disabled' does not result in inappropriate diagnostic approaches and procedures.

He explained two common issues in this area: differential diagnosis and diagnostic overshadowing.

Differential diagnosis is defined as 'the possible diagnostic options within a range of conditions or diseases'. In other words, the term learning disability includes a wide range of conditions and behaviours - there is a need to differentiate these in order to find the appropriate treatment or care.

Diagnostic overshadowing is 'the inability to see possible ill-health and conditions that may be present beyond the learning disability.' In other words, a health condition, which may have nothing to do with the person's learning disability, is not diagnosed because the condition is assumed to be due to the learning disability.

3.3

However there can be particular issues for people with complex needs, for example in communicating health problems. People need to be supported in giving and receiving information and in making decisions about their health care. This is essential in primary care settings, so that health needs are recognised and treated at sufficiently early a stage, and people do not progress to palliative care settings because of inappropriate diagnostic approaches. In Part Two we report on Dr Claud Regnard's work in this area.

3.4 Philosophical barriers

3.4.1 A 'death making culture'

Linda McEnhill outlined the ideas of Valerie Sinason, a psychotherapist working at the Tavistock Institute, which suggest that people with learning disabilities live in a 'death making culture' (Sinason, 1996). By this she means that the messages sent out by the media in many cases imply that it is a tragedy for a person with a learning disability to be born. Older mothers are encouraged to take tests and to consider terminations. Births are not celebrated. Many people with learning disabilities grow up with the messages 'people like me shouldn't exist', 'I shouldn't be here', 'Mum's life would be better without me.'

Linda considered that this is often the backdrop for someone facing terminal illness. It can stop people taking action to prevent disease; it can stop people thinking they have a right to prolonged life; it can create a culture where some people with disabilities and carers may secretly believe that life is not valued and death is a blessing.

3.4.2 Keeping secrets

Hollins and Grimer (1988) in "Going somewhere", suggest three secrets commonly kept from people with learning disabilities:

- that they have a learning disability;
- that they are sexual;
- that they are mortal.

Linda McEnhill wondered if we keep the same secrets from providers of services. If mortality is a secret, no one is prepared for facing death - neither the person with a learning disability nor his or her carers. If sexuality is a secret and a taboo, no-one plans for associated services, cervical cancer screening is not carried out and preventative treatment may not be provided.

3.4.3 Powerful Myths and Taboos

Linda spoke about a Mencap report (Mencap and the NHS, 1998). This found that while 85% of the population had received cervical screening, this dropped to 17% of the learning disability population and fell to only 3% of those living at home. Linda felt that the myth that people with learning disabilities are without sexual desire or expression is powerful and has resulted in under-representation in cervical screening programmes.

She also quoted figures from the same report for women with a learning disability who accessed breast screening: 76% of the eligible population had sought breast screening, but this dropped to 50% of women with a learning

disability and only 17% of those living at home. Linda put forward possible explanations for this discrepancy - the problems of accessibility of mammography machines, difficulties of explaining the process and of gaining consent. However Mencap also reported that when women with a learning disability were directly offered screening, take up went up to 90%, which is higher than the general population.

3.5 Disease profiles and information gaps

Michael Brown spoke of genetic based health issues and identification of complex needs which have a particular correlation with learning disability e.g. epilepsy, challenging behaviour. These give rise to a layered health picture for many people with learning disabilities, which in turn presents challenges to the health services seeking to meet their needs.

The main causes of death in people with learning disabilities are cardiac and respiratory conditions and early dementias. Dr Regnard noted that people with Down's syndrome are six times more likely to die than the general population from conditions associated with dementia, diabetes, epilepsy and congenital abnormalities despite being a younger population (Hermon et al, 2001).

Linda McEnhill reinforced the point that in some parts of the country we do not know how many people there are who have learning disabilities. Local authorities are mostly using statistics derived from numbers of people known to them and prevalence rates or other population studies. Information on death and causes of death is poor. So we cannot detect patterns or make links. The new Scottish Consortium for Learning Disabilities is seeking to correct this.

3.6 Barriers for people with learning disabilities who have cancer

Linda McEnhill detailed further barriers in relation to a cancer diagnosis and understanding of its incidence in people with learning disabilities.

3.6.1 Diagnosis and comparisons

Diagnosis is often late due to a number of factors.

- Issues related to the care setting. People may communicate their ill health and disease behaviourally and because this is open to misinterpretation, symptoms may not get picked up.
- Over attribution of learning disability, especially by mainstream staff - equivalent to the diagnostic overshadowing explained earlier.
- Subjective quality of life decision-making.

Comparisons between cancer incidence in people with learning disabilities and the general population are not easy. There are several reasons for this.

- Lower life expectancy of people with learning disabilities.
- Aetiology and factors predisposing particular syndromes to cancer e.g. higher rates of undescended testes or more complex factors.
- Accounting for lifestyle factors - for example, how can the lifestyle of people with learning disabilities, the effects of stress, diet, smoking and drinking be compared.

Linda McEnhill also reported from a recent British Institute of Learning Disabilities (BILD) study commissioned by the Department of Health. The BILD report suggests that there is a lower incidence of cancer in people with learning disabilities (13%) compared with the general population (26%). However this could be due to the fact that people with learning disabilities have a lower life expectancy and cancer is still a disease of old age. There is perhaps a lower incidence of bronchus, prostate and breast cancer.

Gastro-intestinal cancer causes 58% of cancer deaths in people with learning disabilities, a significantly higher incidence when compared with 25% of cancer deaths in the general population. The report suggested that this is partly explained by the fact that 70% of people with learning disabilities suffer from gastrointestinal reflux. However Linda also referred to possible links to the H Pylori bacteria, and to the presence of this in people who live or have lived in institutions.

The BILD report, [Cancer and people with learning disabilities \(Hogg, Northfield and Turnbull 2001\)](#) provides a review of current knowledge and practice in this area. However it is largely based on literature review. Although it includes the views of people who plan and commission services and health care professionals, the sample size was very small and Linda suggested that an early review and further studies would be useful.

3.6.2 Cancer and people with Down's syndrome

Linda McEnhill reported that women with Down's syndrome appear to be less vulnerable to breast cancer. It is not clear if there is a genetic factor behind this.

Malignancy is at least as common in people with learning disabilities as the general population while people with Down's syndrome are more likely to have leukaemia (Patja K et al, 2001). They have a very significantly increased risk of childhood leukaemia, of between 10 - 30%.

3.7 End stage Down syndrome

Restating that 80% of people with Down's syndrome can be expected to live until over age 50, Dr Regnard pointed out that the end stages of Down's syndrome have a different pattern to cancer. This means that the way in which care is delivered has to be different. End-stage Down's syndrome is characterised by a rapidly progressive dementia and end-stage symptoms of dysphagia and accompanying chest infections are common.

3.8

This combination of philosophical barriers, changing health needs and particular disease profiles starts to define the challenges for practice and for developing and improving services.

4 Challenges for practice and models for overcoming barriers

Michael Brown and Linda McEnhill listed the challenges in key areas before going on to give some examples of models seeking to address them. Part Two also explores some of these issues in more detail.

4.1 Equality of access to treatment

Some of the figures on screening and on health inequalities detailed by Michael and Linda illustrate the barriers to people with learning disabilities having equal access to health provision and treatment. Linda McEnhill reflected on some reasons for this.

4.1.1 Assumptions are made about:

- lifestyle and the presumed quality of life someone has;
- ability to consent to treatment;
- ability to cope with treatment.

There are no reasons to make these assumptions yet they may be used to deny or delay treatment.

4.1.2 Decisions and concerns about quality of life

- Parents may be concerned about the quality of the person's life when they are no longer around. Family carers aged over 65, often doing intense physical care, care for 25% of people with learning disabilities. Many have fought all of their lives to get services or fair treatment, so they are naturally fearful of a future for their son or daughter which does not include them.
- Professionals and others may make subjective decisions about the presumed 'quality of life' of someone with learning disabilities.

4.1.3 The challenges

Linda summed up core challenges in ensuring equal access to care and treatment.

- How can people be enabled to access the services they need and to which they are entitled?
- How should problems of organisational culture and poor attitudes towards people with learning disabilities be tackled?

Sharing ideas – equal access to health screening

In Glasgow the Primary Care Liaison Team (PCLT) is offering learning disability awareness training to primary care and health centre staff. The approach taken by the PCLT, in collaboration with other agencies, seeks to raise awareness, skills and competence. The aim is to improve access to primary care in ordinary health care settings for people with learning disabilities, who increasingly live in ordinary communities throughout the city.

The attitudes, values, and communication training has been designed in consultation with people who have a learning disability and is co-facilitated by someone who has a learning disability. The training is received in local surgeries or health centres or as part of an LHCC protected learning event and accompanies a health check rollout programme for adults with learning disabilities.

Contact: Nicola Robinson, Primary Care Liaison Team, 109 Stravanan Road, Castlemilk, Glasgow, G45 9UT. Telephone 0141 211 0835.
Email: nicola.robinson@glacomen.scot.nhs.uk.

4.2 Issues of consent

There are challenges in supporting people to make their own decisions.

- What about consent? Whose decision is it anyway? How can people be assisted to give 'informed' consent and to have a voice and choice, including access to independent advocacy?
- How does the Adults with Incapacity (Scotland) Act 2000 help or hinder in dealing with consent issues?

Part Two provides more information and discussion on this subject.

4.3 Providing information and appropriate services

Michael Brown considered challenges in sharing information and expertise.

- Profound and multiple impairments are often life limiting conditions. How do carers know and learn about health and palliative care needs and services?

- What about staff in the acute sector? How well does this service and culture deal with the needs of people with learning disabilities? This question is being included in the current review of acute services in Glasgow.
- How do health service professionals know someone has a learning disability in order to ensure appropriate services are provided?

The Lothian Collaborative Model

In 1996, Edinburgh's Western General Hospital and Edinburgh Healthcare initiated a collaboration between the acute service (Lothian University Hospitals Trust) and the primary care service (Lothian Primary Care Trust). This involved a series of linked tools.

- Joint primary and acute care protocols.
- Use of a 'Dependency Assessment Tool', which helps people working in the acute service to be aware of other issues and needs e.g. challenging behaviour.
- Employment of a Learning Disability Liaison Nurse (the first in the UK) to work across the health care settings - acute and primary care settings, clinical oncology units, hospices, palliative care. The availability of this expertise helps to improve the experience of people with learning disabilities in acute settings.

Further information can be found in the article by M Brown and J MacArthur 'Discriminating on grounds of need not disabilities', Nursing Times, 1999, volume 95, number 29, pages 48 -49. A fuller description of the approach is described in 'A Collaborative Approach to caring for patients with a learning disability in the acute hospital' (March 2002), adapted from the Guidelines and Assessment tool developed by Lothian University Hospitals Trust and Primary Care NHS Trust. It can be downloaded from www.fons.org/network/nlnldn/a2a/app3.pdf or telephone 0131 537 1000.

4.4 Placement issues

"Clients with a learning disability have a right to live in the community - but not a right to die there."
Staff member, Northgate and Prudhoe NHS Trust

Linda McEnhill quoted this perception of a member of the Northgate team about the reality for people with learning disabilities who are terminally ill. She considered some of the obstacles which impede palliative care at home.

- **Registration Issues**

Many people with learning disabilities live in shared or group or hostel accommodation described as registered residential care.

Before April 2002 the regulation of care was carried out by 32 local authorities and 12 mainland NHS Boards. They had different standards and procedures which sometimes stood in the way of enabling nursing care to be provided in a residential care setting. However the Scottish Commission for the Regulation of Care (the Care Commission), was set up under the Regulation of Care (Scotland) Act 2001 to put in place a new unified system of regulating care which focuses on the best outcomes for people. This should mean that the level and type of care provided, and where it is provided, is determined by individual need.

- **Lack of knowledge**

People, staff and carers lack knowledge about resources and about rights. The GP is a key resource and link to other resources. Palliative care staff may assume that those caring for a person with learning disabilities know everything about the person, but they may not.

- **Lack of confidence**

Learning disability staff may lack the confidence to question and challenge primary care and secondary providers of palliative care.

- **'Home for Life'?**

People with palliative care needs challenge this concept. Where someone shares accommodation, there can be conflicting demands from other service users.

4.5 Communication issues

Linda McEnhill pointed out that, in a verbal society, many people struggle to understand those who do not use language as their way of communicating or understanding. Carers may forget to check whether the person can understand spoken language even if the person's own expressive skills are poor.

Even if someone does use language, it is important to check how they use it and use family members, carers and learning disability professionals to find out if the person is a 'concrete' or an 'abstract' thinker. Linda pointed out that "The world of palliative care is a world of abstraction and euphemism." She described the difficulties of using abstract speech to communicate with someone who understands literally and the risk thereby of failing to communicate. She gave an example of an alternative interpretation of the commonly used term 'side effects'.

“It’s very difficult having sickness and diarrhoea together - because you don’t know which one to do first! The doctors call this a ‘side effect’ but [it doesn’t just affect your sides]...it affects your whole body!”
Spoonface Steinberg (BBC)

4.6 Pain assessment and symptom control

Dr Regnard said that estimates suggest that 3,825 people with central nervous system or mental disorders die each year in severe symptom distress.

People with a learning disability are as likely to suffer distress and pain as other patients but are likely to have poor access to pain control and other support. They may also have difficulty communicating that pain and distress. There are therefore significant challenges in knowing how to assess pain and distress and how to help people with pain control. These are considered in more depth in Part Two.

“Don’t dive alone”

The National Network for the Palliative Care of People with Learning Disabilities

In November 1998 a group of people came together and decided to set up a network for people involved in the palliative care of people with learning disabilities. The Network aims to:

- overcome individual practitioner isolation -“let’s stop pushing the same boulders up the same hills and share experience”;
- link and replicate good practice;
- collate and record instances of poor practice;
- more effectively influence practice and policy in both palliative care and learning disability services.

It does this by:

- linking individuals into regional groups for regular meetings to provide information and support and a forum for collaboration;
- providing two national study days a year;
- advising on resources (to telephone enquirers)and developing projects.

The network now has a constitution and a subscription membership system. It is seeking to improve accessibility to the network and to widen representation on it, in particular from people with learning disabilities and carers. It is also trying to enable dialogue across the boundaries of policy and service delivery and across international boundaries.

It is developing a website and in the meantime the network can be contacted through the page hosted on www.helpthehospices.org.uk

5 What is the picture?

Part One has shown a picture of palliative care for people with learning disabilities that seems incomplete. Basic information is lacking about numbers of people with learning disabilities, where they live and why and where they die. There are many reasons why palliative care services and learning disability services have not made links to share expertise and experience. More work is needed to enable and maximise the capacity of people with learning disabilities to have a voice and to make choices. Many people with learning disabilities are not accessing routine screening, have difficulty communicating illness and their opportunities for becoming involved in and responsible for their own healthcare appear limited.

Certain common threads run through the picture:

- communication;
- consent, choice and control;
- spirituality;
- supporting and understanding death and dying.

The same themes are repeated in Part Two where we look more closely at three aspects of palliative care for people with learning disabilities:

- pain assessment and symptom control;
- consent and the Adults with Incapacity (Scotland) Act 2000;
- spirituality and support in death and bereavement.

Part Two
Finding the Words

6 Finding the words - pain assessment and control

6.1

Information on health inequalities and disease profiles put forward by Dr Regnard, Michael Brown and Linda McEnhill in Part One suggested the barriers and challenges for palliative care services for people with learning disabilities. Dr Claud Regnard gave an insight into the difficulties of assessing and responding to the pain and distress experienced by people with learning disabilities. In some cases the facts seem to be conflicting and confusing. Dr Regnard said that there are paradoxes to address in order to identify, assess and relieve pain for people with learning disabilities.

Pain assessment tools

Why do we need tools? Jo Hockley spoke about a woman with communication problems who expressed pain through aggression. The woman had a prolapsed uterus that it took 10 weeks to diagnose. She changed GP and with the help of an advocate accessed the necessary treatment. Once treated, she was a changed person. Someone able to communicate pain verbally would have been admitted to hospital immediately. Lack of knowledge in health services about how to recognise pain and how to treat people with challenging behaviour leads to failure properly to diagnose and treat.

Jo Hockley outlined some of the behavioural assessment tools for detecting pain.

- DisDAT: Disability Distress Assessment Tool (Regnard,2003).
- DS-DAT: Discomfort scale of dementia of the Alzheimer type (Hurley et al 1992).
- DOLOPLUS 2 Scale (Lefebvre- Chapiro S. 2001): this lists types of behaviour e.g. somatic reactions, psychomotor reactions and psychosocial reactions.

6.2 Paradoxes of pain

Dr Regnard posed seven paradoxes raised by research and statistics on cancer, pain and distress and people with learning disabilities.

First: In the UK, up to 66% of cancer patients have distressing pain and only 40% reported adequate pain relief (Addington-Hall & McCarthy, 1995) BUT clients with learning disabilities have poor access to screening (Aspray TJ 1999) and are likely to have poor access to pain control and other support. So if people who can communicate have difficulty in communicating their pain and in getting help to relieve it, where should efforts be concentrated in relation to people with learning disabilities?

Second: Pain and other symptoms are common in advanced cancer patients BUT they are also common in adults and children with advanced, non-cancer disease, such as AIDS (Addington-Hall & McCarthy 1995, Hunt et al 1995). People with learning disabilities with advanced cancer and non-cancer will also have pain and other symptoms.

Third: Distress can be a feature of advanced disease BUT very little work has been done on identifying distress in patients with learning disabilities.

Fourth: The numbers of adults with learning disabilities is increasing by 1.1% each year, probably because people are living longer BUT there is no plan for coping with those who will die from primary, secondary and related diseases or for coping with illnesses arising as a consequence of older age.

Fifth: Much research on people with profound communication difficulties has been on pain BUT there is no evidence that pain has specific signs or behaviours, so how is it possible to produce a pain assessment tool? Pain 'expressions' are useless without knowing their context - for example, anticipation of pain plays a role in pain expression, but some people cannot remember pain, such as some people with dementia.

Dr Regnard wondered why health professionals and researchers concentrate on pain rather than distress? Perhaps it is because distress is seen as vague and therapeutically frustrating. Identifying pain supports pain treatment programmes. It identifies pain as one symptom that immediately suggests a treatment. However there is more than one sort of pain and different sorts of pain need different sorts of treatment.

Sixth: Many pain tools have been validated in people with poor communication BUT they have been tested in situations where pain is common, for example in post-operative situations, during procedures, or where disease is advanced.

Dr Regnard regards these as self-fulfilling validations of the pain tools. They have not been used in situations where the person could actually be experiencing distress rather than pain.

“Just because one expression is pain in one situation, does not mean it is pain every time that expression is used.”

Pain and distress - spot the difference?

Published signs and behaviours associated with pain or distress include:

Pain

Facial expression, vocalisation
Behaviours (aggression, withdrawal)
Change in posture
Change in activity
Autonomic changes (such as being pale or sweating)

Distress

Facial expression, vocalisation
Behaviours (aggression, withdrawal)
Change in posture
Change in activity
Autonomic changes

Why would there be a difference? Pain is distressing.

Seventh: For a given person, there may be a limited repertoire for both expressions of pain and response to it. However carers appear to have the skills to identify distress. In fact they are very good at it because they notice change BUT they have little understanding or confidence in those skills.

Dr Regnard implied that there is as great a need to increase confidence in identifying pain as to develop tools for identifying it.

6.3 'It's distress - what now?'

Recognising the paradoxes means recognising that pain assessment tools may not give all the answers. Rather Dr Regnard proposed the development of a documentation tool that can look at signs of distress and behaviour and changes in these to learn the individual's language of pain.

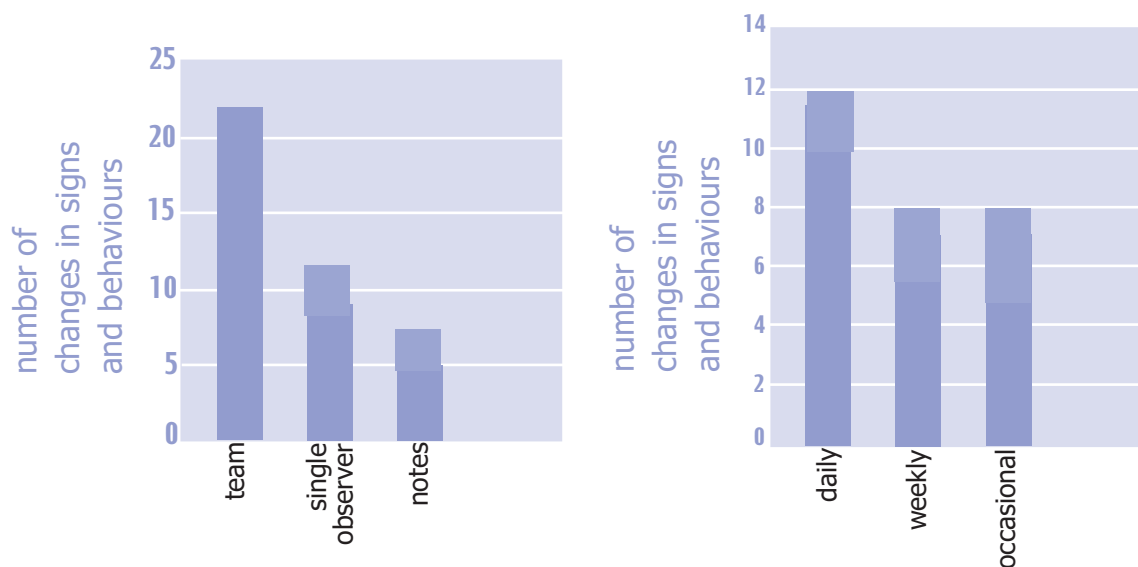
He reported on studies carried out with people who have no words although they may vocalise. These include the following elements.

- Document distress signs and behaviour and check these against previous episodes. The recording needs to be clear and regular.
- Note the context and pattern of changes.
- Apply clinical decisions.

- Decide on likeliest cause.
- Run trial of management.
- Recheck signs and behaviour against the original documentation.

This was illustrated showing documentation of signs and patterns in facial appearance, vocalisation, skin, eyes, posture, habits or mannerisms, autonomic areas, teeth/jaw, speech and tongue movements. One study looked at the difference in changes observed in case notes by a single observer and by a team of people and detailed in case notes. This showed where more people were involved, more changes were detected. Different people detect different and more signs of distress.

Finding the words for pain and distress



A related analysis examined the number of changes detected with daily observation, weekly observation and occasional observation. There is less difference than might intuitively be expected. It does not need someone to see the person every day to detect changes in signs or behaviours. In fact, Dr Regnard suggested, daily contact can lead to habituation and failure to notice.

6.4 Clinical decisions

Once the patterns have been documented, then new signs or behaviours and changes in the signs and behaviours have to be carefully documented to inform clinical decisions.

Observation needs to consider whether the new sign or behaviour is:

- Repeated rapidly?
- Associated with breathing e.g. deep breaths only?

- Worsened or precipitated by movement e.g. as might happen with a fracture?
- Related to eating?
- Related to a specific situation?
- Associated with vomiting?
- Associated with elimination?
- Present in a normally comfortable position or situation?

Repetition of the new or changed behaviour is important. Each of the above queries has a sub-section of further queries, all aimed at determining if they are communicating physical symptoms.

Another function of this approach is to use the patterns of behaviour as a language, which helps in detecting warning signs so that clinical decisions can be made before the person is communicating full distress. For example, when a person is happy, their usual pattern may be to make eye contact and staring eyes may communicate distress, while a period when no eye contact is being made may give a warning of early distress.

More work is being carried out on this approach to pain assessment and this will be reported.

Person centred planning, pain assessment and control

In Jo Hockley's workshop session, there was debate about the potential use of person centred planning tools as an approach to recording and communicating how a person shows signs of distress.

It was felt that while Essential Lifestyle Planning (ELP) can be useful for transition planning, it is not effective if it is used as a 'tool' or for long term planning. Person centred approaches can be integrated into daily care tasks and can record how a person shows signs of distress. How then can this information be transmitted to hospital staff at or prior to admission?

One suggestion was that patient held records could help - an approach which has been used effectively in cancer care - for example recording what analgesics have been used and been effective in the past. However in the Glasgow Healthy Cities project suggestions of patient held records and 'communication passports' had been strongly opposed.

7 Death, dying, loss and grief

7.1 Putting the person at the centre: looking at imaginative ways of supporting people through loss and grief

Mark's Story

Mark is twenty-seven years old and has communication difficulties due to being deaf. He uses 'sign-a-long' to communicate but only uses the signs that are important to him. His Dad has died suddenly of a heart attack and support staff need to explain this to him and explain the funeral to him.

Participants at a workshop led by Belinda Paris worked together to think about Mark. How could he be supported to understand the death of his father and to deal with his loss and grief? How could he be included in all aspects of bereavement? They considered several inter-related issues and some of their thoughts and ideas are summarised below.

7.1.1 Why is it important to include people with learning disabilities in the death of someone close to them?

These are some of the things people said.

- Death is a normal part of living and people with learning disabilities have the same right to receive and give comfort to others, to feel and share grief, to express frustration and anger. People need to know that there is no shame in grieving and that they were not responsible for the person's death.
- Being included in the rituals and symbols around a death helps the person to understand and accept that the person is no longer there and to prepare for the future.

7.1.2 What gets in the way of professionals actively supporting people to understand death and express grief?

- Some people voiced their own discomfort with and fear of death. They felt that people might not know how to deal with it for themselves and may have little experience. They are scared and embarrassed by their own emotions.

- People expressed fear that they would not explain death properly, that the person will not understand and staff may not have all the answers. There is a fear of 'getting it wrong'.
- People worry about how the family will react to the approach taken. They worry about how to cope with any behavioural backlash from someone facing loss and grief.

7.1.3 Joint working with others who are or can be part of the process

The workshop groups shared their practical experience and advice.

- The person is not alone and neither are members of the support team. Involve and support other family members. If the person is sharing a home involve his flatmates, or other friends.
- Try and be consistent within the support team and use the strengths of the support team, such as the person who has the strongest relationship or knows the person best. Key worker staff may need skills training in this area.
- Sometimes it helps to talk to or be with someone else who has experienced death. It might be appropriate to involve people from outside the close family or support network, such as CRUSE Bereavement Care. Members of a support team might also find it helpful to talk to others who have supported someone in dealing with loss and grief.

7.1.4 Practical and person centred ways of supporting people

People thought about the different steps in dealing with death and bereavement and again shared experience and advice.

Breaking the news

- This is a first job that needs to be done by a trusted person - a family member or someone in the support team, in a suitably private place unlikely to be disturbed.
- Be open and honest about what has happened but allow time and space for information to sink in.
- 'Do it in bits' and think about who else needs to be involved or told.

Understanding death and funeral arrangements

- Think about whether viewing the body would help the person to understand.
- Perhaps start by relating death to other loss situations - friends who have gone, support staff who have moved on.
- Find out if the person knows anyone who has died - a grandparent, a neighbour. Use photographs of people the person knows who have died or relate the issue to a favourite T.V show or movie, for instance.
- Involve the person in preparing for death and in the funeral arrangements, with family contact where possible.

Saying goodbye and remembering who has died

- Honour and respect the person's own beliefs and consider spiritual and religious beliefs and involving relevant people, such as a minister.
- Include and support the person in funeral preparations if practicable - choosing coffins or music.
- Utilise other senses e.g. specific smells; look at familiar items, which may remind the person of the one who has died; go to places they went together.

Communication tools

- Use simple language, and go beyond words with visual aids and pictures, or use art and drawing to communicate.
- A communication board or memory book may help.
- Use signs the person understands, even those he does not use.
- Use an expert in communication e.g. speech & language therapist or learning disability nurse if no one else is able to communicate.

Supporting loss and grief

- Be pragmatic. No one can remove the pain of bereavement, only support and facilitate the grieving process. Recognise that grief does not necessarily ever end - it may be important to go back to the issue at a later date, using prompts such as 'when mum died...'

- It will help if support staff and family members can keep good communication going between all involved and plan and prepare for likely or possible reactions.
- Support staff should know what the person finds reassuring and comforting. They should use this. It is also important to document this so that this information is available should staff change.

7.2 Death, dying and the spiritual lives of people with learning disabilities

In Belinda Paris's workshop, the need to recognise spiritual needs was raised in the context of understanding and coping with someone else's death. Participants felt that spirituality is an overlooked dimension by people who work in hospice settings and by those who work in the community with people with learning disabilities and carers. Dr John Swinton facilitated workshops which explored the particular role of spirituality in palliative care.

7.2.1 Understanding Spirituality

"I won't be needing spiritual care...I'm not religious."

Everyone has a different idea of what spirituality is. Dr Swinton and others put forward some definitions.

- It is the structure of significance that gives meaning and direction to a person's life and helps them deal with the complexities of human existence.
- It is a driving force, a way of being, and an inner self - perception of who you are in the world.

Dr Swinton suggested that personal structures of significance, whether these are religious or not, give people a framework for understanding life events. Illness is a profound challenge to one's sense of self and spiritual structures are often used to make sense of illness and to rebuild this sense of self in a new world of illness or terminal illness.

He spoke about a report by David Hay and Kate Hunt, [The spirituality of people who don't go to church \(2000\)](#), which shows that people can see themselves as spiritual without necessarily linking this to religion. Dr Swinton suggested that while people are becoming less interested in formal religion, in 'joining' things, they are looking for ways of finding hope and meaning. They are moving towards a more personal and individual understanding and pursuit of spirituality.

7.2.2 A space to listen

There has been little research on whether people with learning disabilities follow this trend. Dr Swinton carried out a pilot study for the Foundation for People with Learning Disabilities. The results of this were published in the report [A Space To Listen: Spirituality and the lives of people with learning disabilities](#). It was clear that the people with learning disabilities who participated in this project were very spiritual and they turned to spiritual things in times of distress and times of happiness. At the same time, it was significant that carers and supporters often had no idea that the people they were working with, and for, felt like this. It did not occur to them to explore this dimension of the lives of people for whom they were caring.

The results emerging from an ongoing two-year research study, by Dr Swinton, assisted by Elaine Powrie, support the pilot study's original finding that there is a need to revise and expand the notion of the spiritual lives of people with learning disabilities.

People Want Spiritual Care!

It is an ethical responsibility of all carers to recognise and respond to spirituality as it is presented in all human beings. It is a right enshrined in the Human Rights Act.

Carers and support workers must be equipped to recognise, understand and deal with this dimension.

Dr John Swinton

7.2.3 Grief is grief whoever you are

The Gallup International Institute carried out a national survey (1997) which reported on 'Spiritual beliefs and the dying process'. The key spiritual concerns mentioned by people surveyed were:

- not being forgiven by someone for something they had done;
- not having a blessing from a family member or religious advisor;
- questions about life after death.

The reassurances that gave people comfort related to these concerns. Desire for reconciliation with those they have hurt, or who have hurt them, and belief that death is not the end but a passage, figured strongly in responses.

The dying process itself takes people on a new journey of spirituality.

There is no evidence base yet around people with learning disabilities and spirituality, when they are dying or dealing with the death of others. However the early findings of Dr Swinton's research show that people with learning disabilities are no different from the general population in their spiritual concerns and need for comforting reassurances.

Watching Mum leave from behind the curtains

A 35-year-old man lived with his mother, who died. The family decided it was best he didn't go to the funeral. He was locked in the living room and just saw his mother being taken away in the hearse. He was taken into care where he started to act very aggressively.

The family was well meaning and intending to protect a vulnerable person through avoidance - 'it will be too upsetting for him'.

In Dr Swinton's workshop the point was made that sometimes challenging behaviour in people with learning disabilities can be traced back to long unresolved grief which has not been raised or explored.

7.3 The challenges

During workshops, presentations and discussion people considered the challenges of acknowledging and respecting the spirituality of people with learning disabilities who are dying or dealing with death and bereavement.

Questions and challenges

How do you help someone who is dying when you do not know anything about his or her spiritual background or what is likely to be worrying him or her?

Some ideas put forward

Work with the wider group of people who know the person, for example carers and advocates. Discover their usual responses, know their communication triggers.

Questions and challenges

How do you communicate the idea of death in a palliative care context?

How do you understand and respect choices?

How can professionals be helped to understand the need for spiritual care and provide for this?

Some ideas put forward

Try to understand what the person comprehends of what is happening to them and try to make that meaningful.

Simply be with the person.

Be open about what is happening.

Use visual aids, Makaton, Boardmaker.

Acknowledge and use carers and family members - relationships are important.

More independent advocacy services are needed to work with people in health care settings.

Help professionals to recognise their own spirituality as a foundation.

Remember that being there can help.

Remember that being there makes a difference.

Common Knowledge is developing an e- learning and interactive resource for adults with learning difficulties. Called 'What happens when someone dies?' it helps an individual to both understand their own death and that of others.

7.4 Care of the spirit and palliative care

Dr Claud Regnard expressed the spiritual dimension of different stages of palliative care patients.

In the early stages - hope for a cure.

Later - hope for control, hope for comfort.

At the end - hope for peace.

Some people move naturally through these stages, some need help. Dr Regnard suggested that the difficulty for many professionals is that they are 'fix it' people and being present through a spiritual journey is hard.

Spiritual care relates to a way of being with people, which embodies and acts out the possibility that what is happening now may not be all that there is; that the veil of pain and disorientation can be lifted to reveal hopeful possibilities for the future, irrespective of how long that future may be.

Dr John Swinton

8 Control, consent and the Adults with Incapacity (Scotland) Act

Dr Rosaleen Beattie facilitated a workshop that considered issues of control and consent in relation to medical interventions, palliative care and the impact of the Adults with Incapacity (Scotland) Act 2000. Extracts of an article prepared by Dr Beattie are reproduced in Appendix 4 and give more detail on the principles of the Act, requirement to consult and medical treatment certificates.

8.1 The Adults with Incapacity (Scotland) Act 2000

Part 5 of the Adults with Incapacity (Scotland) Act 2000 is a statutory framework for the medical treatment of incapacitated adults, which took effect from 1st July 2002. The Act introduces new forms of proxy decision-making, and clarifies the legal basis upon which doctors make decisions on behalf of incapacitated adults.

The purpose of the Act is to protect the rights and interests of the most vulnerable and voiceless members of society. It does this by providing a framework whereby decisions can be made on behalf of adults who are incapable of managing their own affairs because of mental disorder, or inability to communicate. At the same time it tries to support vulnerable people to exercise the greatest possible degree of decision making and autonomy over their lives.

Part 5 of the Act places a new legal responsibility on the doctor who is primarily responsible for the care of an adult to assess their capacity to reach a decision in connection with medical treatment. This means doctors have to learn to take a different approach in order to comply with an Act that aims to enable patients and uphold human rights.

8.1.1 Background

Without consent, medical treatment may be regarded as a form of assault: it is consent that makes medical treatment lawful. In order to be valid, consent must be given by a competent person, be informed, and be free of coercion (General Medical Council, Seeking Patients' Consent: The Ethical Considerations). This means being able to understand the proposed intervention, evaluate the consequences of a decision, and then express it.

All adults are presumed to be competent to make decisions on their own behalf - in Scotland this includes everyone over the age of 16 years. For those adults without capacity to give consent because of mental illness or learning disabilities, no one could previously give consent on their behalf. All medical treatment was carried out on the basis of its being in the 'Best

Interests' of the adult in the opinion of the medical practitioner proposing the intervention or treatment. However this was a wholly medical decision, and families and carers, as well as incapable adults themselves, felt isolated and disempowered.

8.2 Assessment of capacity

In relation to any particular medical intervention, to assess capacity, the clinician must judge whether the adult:

- understands the nature and purpose of the proposed treatment;
- is aware of any alternatives;
- understands the likely risks and benefits;
- is aware of their right to, and how to, refuse, as well as the consequences of refusal;
- is capable of making and communicating their choice;
- is expressing views consistent with their previous moral, cultural, family and experiential background;
- is making a choice which is free of coercion.

Capacity is task specific, and will apply to the ability to make a decision on the particular medical treatment proposed. Capacity is 'all or none' only for a single situation, not for all situations. Where the treatment or investigation is complex, or associated risks and side effects are likely to be severe, greater capacity is required in order to give a valid consent, and assessment needs to be more stringent.

There is no template or algorithm for assessing capacity, which has been validated for Scotland. The only guidelines are to be found in the Code of Practice for persons authorised to carry out medical treatment or research under Part 5 of the Act and these supersede any previous guidance. Further details of this can be found in Appendices 2 and 4.

The emphasis in the Act is on enhancing capacity, not intervening unless incapacity is proven and enabling the person to understand and communicate. This might take place with or through someone who knows the person very well.

8.3 The principles of the Act

The Act contains new provisions authorising the doctor primarily responsible for the medical treatment of an incapable adult to do what is reasonable, to safeguard or promote the physical or mental health of that adult. The term 'Best Interests' is replaced, in favour of 'Benefit'.

The legislation places great emphasis on enabling the adult with incapacity to exercise the greatest possible degree of decision-making and autonomy over their lives. Before carrying out any medical intervention, the doctor primarily responsible for an incapable adult's care must check that the proposed treatment complies with the principles of the Act. The person must be put first, not the condition or the plan for medical treatment. Applying these principles represents a significant learning curve for medical and other professionals.

The five core principles

Benefit - There should only be an intervention in the affairs of a person if the intervention will benefit the person and if intervention is the only way of achieving the benefit.

Minimum Intervention - If an intervention is to be made, then it must be the least restrictive option in relation to the freedom of the person.

Wishes and Feelings of the Adult - The past and present wishes and feelings of the person must be taken into account in deciding whether to intervene and, if so, in deciding what intervention action to take. This must be done using the means of communication appropriate to the person.

Consultation with Relevant Others - Account should also be taken of the views of people who have an interest in the welfare of the person or an interest in the proposed intervention. This includes the nearest relative and primary carer as well as any other person with an interest who has made their views known. More details on the requirement to consult are given in Appendix 4.

Encourage the Adult to Exercise Residual Capacity- Individuals unable to make decisions on medical treatment may be able to make decisions on other aspects of their care, and should be encouraged to do so.

8.4 Application of the Act to palliative care

In the palliative care setting, most judgements on a patient's capacity to consent to the treatment proposed would be quite straightforward, and arise as the patient's condition deteriorates. However, what was previously an intuitive assessment of a person's capacity to make decisions about medical treatment, will now be required as explicit practice by the Act.

Most decisions will be based on an obvious clinical situation where impaired capacity has been discussed within the team. Although a medical decision is being made, it is vital that the opinions of other professionals within the team are sought and the discussion and decision fully documented. Where real doubt exists, this will usually be against a background of continuing disability such as learning disability or dementia, and in such cases an expert opinion might be sought from an appropriate specialist. Those with long-standing and profound disabilities may well have a welfare guardian already appointed.

If someone has communication difficulties doctors may need to rely heavily on the people who know them and must maximise their capacity to communicate and consent, for example considering issues such as varying capacity with time of day, environment or the presence of strangers.

The doctor primarily responsible for the management of the patient must complete a Medical Treatment Certificate of Incapacity under Section 47 of the Act for the incapable adult. This applies even if there is a proxy with the power to consent, such as a Guardian. 'Medical treatment' means any procedure designed to safeguard or promote the physical or mental health of the adult.

Although there is no legal requirement to fill in the form, without it treatment lacks justification, and it would be very difficult to defend an action of assault or negligence, where the principles of the Act had been disregarded. The Medical Treatment Certificate protects both the adult with incapacity, and the doctor who proposes treating the adult.

8.5 Enabling patients or disabling doctors?

The Adults with Incapacity (Scotland) Act 2000 is intended as enabling legislation to support the human rights of a vulnerable section of society.

The conference concluded that overall the Act encourages a person centred and balanced approach, which enables patients and carers and enables doctors too. However workshop participants suggested improvements, in legislation and in practice.

- Extend who can invoke the Act, including the nurse in charge if nursing intervention is required.
- Medical practitioners need to keep the emphasis on documenting the person's decision or opinions and not simply record discussions.
- Wider professional education on the Act and Code of Practice is required - doctors need to realise they do not need a psychiatric assessment before they complete the medical treatment certificate.
- Information needs to be made more accessible.

Part Three

Taking action - where to from here?

9 Taking stock

9.1 Fiona Cathcart presented an overview of the conference subject with an interesting perspective.

Every so often an overwhelming and tragic event occurs - the King's Cross fire, the Lockerbie disaster - affecting significant numbers of people and receiving huge media attention. We think about how people react to traumatic incidents and to the resulting bereavements. Teams of trauma counsellors are assembled to help and minimise psychosocial damage. Some survivors comment the experience has caused them to reassess priorities and to value relationships more because they have learned life is so fragile.

Statistically it is probable some incidents might have included people with learning disabilities but if so they have been absent from subsequent research publications. People with learning disabilities experience the same range of anticipated or sudden losses and tragedies but current evidence as well as the experience of the conference speakers and participants indicates that services are not sensitive to their needs. Early studies indicated that people with learning disabilities who are bereaved could benefit from intervention (Oswin 1981, Cathcart 1991) and this has been confirmed by later research (Hollins and Esterhyzen 1997).

Being alongside

When John's mother died, he was living in an institution and people around him thought it was best if he didn't know that his mother was dying. So he wasn't with the family at the hospital where she died and the staff in the institution thought the funeral would upset him - so he didn't go to the funeral either. He just didn't see his mother again. This was common and accepted practice.

Ten years on his father was dying. This time John was at the hospice, waiting outside his father's room while other family members and a nurse were inside. The doctor came along and said 'you should be in there' and John went in. He was included as an ordinary member of the family in the death of his parent.

9.2 Then and Now

Fiona revisited the recommendations made in her paper [Death and people with learning disabilities \(1995\)](#) She considered what progress had been made in addressing the needs of people with learning disabilities and their carers in facing death. This overview also reflected on the observations made by the speakers and participants at the conference.

Then	Now	Overview
Narrow research base	Slowly expanding research base	Every speaker referred to this. From a research perspective, people with learning disabilities remain invisible and there is ignorance of their needs. There is a limited evidence base. Earlier studies noted IQ and age but neglected other factors known to affect bereavement outcome, for example the type of death and nature of the relationship.
Few policy and practice indicators	Policy and practice are changing but based on limited research.	National policy agendas, such as 'The same as you?' (Scottish Executive 2000) are giving direction and support. SHAS (Scottish Health Advisory Service, now integrated into NHS Quality Improvement Scotland) stated there should be access to screening and SIGN guidelines (Scottish Intercollegiate Guidelines Network) should be followed. This implies access to specialist palliative care also.
<p>What action needs to be taken?</p> <ul style="list-style-type: none"> • More evidential research is needed - qualitative and quantitative - to inform policy and practice development. 		

Then	Now	Overview
<p>Impact of death on both clients and carers was not considered.</p> <p>Counselling services relied on verbal abilities.</p> <p>Insufficient joint training</p>	<p>There is more awareness of the impact of death but uncertainty about how to respond.</p> <p>There is marked increase in illustrated books, videos and audio cassettes. (See Appendices 2 and 3)</p> <p>More training courses are becoming available and national groups such as the National Network (see page 27) raise awareness.</p>	<p>Carers working with people with learning disabilities may have little experience of dying and bereavement and share the unease of their community.</p> <p>Carers of dying and bereaved people may have little experience of people with learning disabilities and not see the person beyond the diagnosis.</p>
<p>What action needs to be taken?</p> <ul style="list-style-type: none"> • Education and training are required in dealing with bereavement and death, in different ways of communicating and using communication tools. 		
<p>Potential for conflict between staff in institutional settings and family members about 'the right way' to die and to mourn.</p>	<p>We are learning to understand difference and to accept different ways of approaching and dealing with death.</p>	<p>The Scottish Executive is funding research into spirituality; we have a broader understanding of this, including learning from humanist settings.</p>

Then	Now	Overview
<p>Complex ethical and legal decisions for people with learning disabilities were still based on old legislation with little acknowledgement of rights and choices about life and death.</p> <p>Communication of pain and symptoms</p>	<p>The Adults with Incapacity (Scotland) Act 2000 gives a framework for making complex ethical and legal decisions based on maximising choice and supporting decision making.</p> <p>We are making progress - some research is helping us to achieve a better understanding; assessment tools have been developed.</p>	<p>We have come a long way from discussions about enforced sterilisation of people with learning disabilities to new legislation which should also underpin decisions about consent in matters of health and illness (Flynn, Keywood and Fovargue, 2002).</p> <p>But there are also risks in misuse of the Adults with Incapacity Act to seek proxy decision-makers instead of supporting decision making by people with learning disabilities.</p> <p>Claud Regnard's presentation and Jo Hockley's workshop have illustrated research findings, but also posed the paradoxes about pain and distress and how these are communicated.</p>
<p>What action needs to be taken?</p> <ul style="list-style-type: none"> • There needs to be understanding and discussion about communication of pain and symptoms across the range of people and professionals in contact with people with learning disabilities. • Wider professional education on the Adults with Incapacity (Scotland) Act 2000 is needed. 		

10 Taking action - suggestions for improving palliative care services for people with learning disabilities

What's the point? Simon's story

Simon is 29 years old, with hearing and sight impairments and learning disabilities. He also has leukaemia. He hadn't communicated his illness and ended up being admitted to an adult ward of an acute hospital. There his cancer needs were assessed. But no assessment was made of his needs as a learning disabled person with sensory impairments.

Before operations, the sign 'nil by mouth' was put above Simon's bed. Simon couldn't read this. If someone puts food down beside him he eats. If he is hungry he will seek out food. So more than once Simon went to theatre having eaten, putting him in danger.

Simon likes to watch TV. There were individual TVs on the ward and on the basis of this Simon was refused a personal TV and video. But the individual TVs were too small for him to see and placed too high for him.

While in hospital, Simon contracted MRSA. He was confined to an isolation room without anyone to be with him. He tried to get up and fell down. He didn't like being alone, so he wandered off. Not surprisingly after his experiences in hospital, Simon now refuses to acknowledge he is ill because he does not want to go to a hospital, where so many bad things have happened to him.

It took 5 months for his family to get him the 24-hour care he needed after he left hospital. His mother eventually took social services to court and took out an injunction against the hospital so that Simon would get one-to-one support on the ward.

People should not have to go to court in order to have their needs appreciated and catered for. We have to do better and we can do better.

Linda McEnhill, 2003

This concluding section draws together suggestions made by the speakers, workshop facilitators and participants about action being taken and which needs to start to move forward from this conference. The suggestions range from work needed at strategic levels to action which health care workers, learning disability support teams, people with learning disabilities and their carers can take locally to improve palliative care.

10.1 What can be done at a strategic level?

Suggestions for the Scottish Executive, NHS Boards and Trusts

- Only 2 out of 15 NHS Boards have carried out any strategic health needs assessments. Most do not know who the estimated 120,000 people with learning disabilities are or their current or projected health needs. Better information is needed in order to plan and deliver better services.
- The Public Health Institute for Scotland was integrated into National Health Scotland on 1st April 2003. The Scottish Executive is already supporting this in undertaking needs assessment to inform and steer the development of services.
- More help is needed to help and sustain families and carers. The new NHS Education may help through better co-ordination of public health education.
- People with learning disabilities use primary and acute health services. However there is very little research and a poor evidence base on the nature of interventions and their effectiveness. The Scottish Executive can support more evidential research - qualitative and quantitative - to inform service and policy development.
- NHS Quality Improvement Scotland has a statutory role to play in reviewing and monitoring health services. Knowledge of practice in relation to cancer and people with learning disabilities is limited. Reviews and monitoring should include not only the experience of health professionals but also that of people with learning disabilities and their carers, and start to build a national picture to identify improvements required.
- The Scottish Executive, NHS Boards and Trusts can support wider education and training for health care and social care staff in the palliative care needs of people with learning disabilities. This could include wider professional education on the Adults with Incapacity (Scotland) Act 2000; development of and training in the use of tools to support communication; dealing with bereavement and death.

- Health is not just about health services. A broad partnership involving social work, housing and the voluntary sector will help to address the palliative care needs of people with learning disabilities. NHS Boards can encourage and facilitate these partnerships.

10.2 What can we be done to improve things locally?

Suggestions for NHS Trusts, GPs, local authorities and social care providers

“The way we practice healthcare is the means by which we demonstrate the value we place on people’s lives.”

- People begin their journey in primary care. Suggestions were made for planners and providers in health and social care to improve the planning and co-ordination of care that evolves from primary care into other forms of care depending on the complexity of people’s needs.
- Make local connections - set up joint study days.
- Develop ‘link’ professionals as a team resource - (see box on page 25 describing the Lothian model).
- Increase knowledge about tools and techniques for understanding the communication of pain and symptoms.
- Accessibility and issues for people with learning disabilities must be considered integrally with mainstream cancer and palliative care services. Professionals need to learn to see beyond someone’s learning disability.
- The local primary care trust, cancer and palliative care networks can develop services which are sensitive to the particular needs of people with learning disabilities.
- Join the National Network (NNPCPLD) for resources, literature, and training (see page 27 and Appendix 3 for details).
- Trusts and other health and social care providers can encourage participation by people with learning disabilities and carers in service development. Look at what people in other fields are doing to involve and consult excluded groups.
- NHS Boards and Trusts and local authorities can support the development of advocacy in their area or service.

10.3 Suggestions for people who work in services and people who use services working together

- Build bridges - make informal links at local level. Everybody is expert in their own field; professionals in palliative care and in learning disability need to speak to one another and learn from one another.
- Trust and respect each other's skills. Acknowledge what you do not know. Investigate joint training opportunities.
- Build up information about services in your area - find out what resources are available. Local hospices may have information services.
- Set up local joint working groups or a learning club.

10.4 Suggestions to help someone prepare for bereavement

- Explore past experiences and understanding of the present situation.
- Consider how much and what information the person wants.
- Consider the concerns of this individual. Remember the carer's concerns may be different.
- Give people information about the rituals and choices that surround death.
- Help people find and keep mementoes of someone who is dying or has died.
- Document the events and experience of the person with learning disability during this time. Record what helped and what was difficult. This will help future carers understand the present situation.
- Stop thinking "what will I do if this person dies?" and think, "what will I do when this person dies?"

Understanding death and dying

The British Institute of Learning Disabilities (BILD) publishes a series of booklets by Fiona Cathcart. These are designed to help people with learning disabilities, and those caring for them to understand their own feelings about death and dying.

- Booklet 1 - Your Feelings
- Booklet 2 - A guide for family and friends
- Booklet 3 - A guide for carers and other professionals.

The booklets can be ordered from BILD whose contact details are given in Appendix 3.

11 Concluding comments

Fiona Cathcart drew the conference to a close with the comment: "There will always be uncertainties in palliative care because there is no 'right way' to deal with death. People choose to deal with death differently and while some may wish to talk about it there are others who do not and their choices need to be respected also."

Carers face difficult decisions with limited resources but the goal of improving the current situation was echoed throughout the day.

Fiona concluded by recalling the lesson that had been learned from planning for major incidents. "We could not plan for a disaster because each one is different but we can plan for working together." This document cannot give prescriptive advice but it can encourage agencies to train and work more closely together so that when there are crises, they can be resolved in more rapid and effective ways.

Appendix 1

Biographical details of speakers and workshop leaders

Dr Rosaleen Beattie

Dr Rosaleen Beattie is Medical Director and Consultant in Palliative Medicine at St Margaret's Hospice in Clydebank. She has a special interest in Medical Law and Ethics, as well as the palliative care of those with learning disabilities. She is a firm supporter of the Adults with Incapacity (Scotland) Act 2000.

Michael Brown

Michael Brown trained as a learning disability nurse in Glasgow and as a general nurse in Fife. He has worked in both general and learning disability nursing and in the community. He is a graduate in Health Sciences and holds a Masters Degree in Policy and Politics from Edinburgh University. He worked for the Chief Nursing Officer for Scotland as the Project Manager at the Scottish Executive Health Department on Promoting Health, Supporting Inclusion. He is currently working with NHS Health Scotland on the learning disabilities needs assessment report.

Michael has a particular interest in the health needs of people with learning disabilities within primary care and acute care settings. He also has a clinical interest in the health needs of men with learning disabilities.

He is a co-author and editor of "Learning Disabilities: A Handbook of Integrated Care", soon to be published.

Fiona Cathcart

Fiona Cathcart is a Consultant Clinical Psychologist with Lothian Primary Care NHS Trust. She has worked with the learning disabilities service in the past and now works in palliative care at St Columba's Hospice in Edinburgh.

Fiona has had a long-standing interest in the problems of people with learning disabilities and their carers who are facing death and dying. She convened a symposium on this topic for the British Institute of Learning Disabilities Annual Conference in 1992 and was commissioned by them to produce a series of three booklets on this subject 'Understanding Death and Dying'.

Fiona has led many workshops for clients and their carers for both statutory and voluntary agencies including Enable, Down's Syndrome Scotland, Elcap and Cruse.

During the last two years she has been part of the Bereavement Research Advisory Group led by Professor Sheila Hollins of St George's Hospital in London. The research will be published in late 2003.

Jo Hockley

Jo Hockley trained as a nurse at St Bartholomew's Hospital, London, in 1970 and then as a midwife. Since 1978 she has specialised in palliative care - first as a charge nurse at St Christopher's Hospice, London, and more recently setting up hospital-based palliative care teams first in London and then in Edinburgh at the Western General Hospital. She obtained her MSc at the University of Edinburgh in 1992. Jo is currently employed as a Research Fellow/Clinical Nurse Specialist at St Columba's Hospice. Here she is working on 'The Bridges Project' that is exploring the introduction of palliative care into nursing homes. Through this 5-year 'action research' study Jo is registered as a PhD student at the University of Edinburgh.

Dr Donald Macaskill

Donald Macaskill is Head of Training and Learning at Scottish Human Services Trust. Previously he was Programme Manager with Common Knowledge in Glasgow. Common Knowledge was instrumental in organising the conference as a result of work undertaken in Glasgow which has highlighted the negative experience of adults with learning difficulties around issues of palliative care. He has also been recently involved in the development of a two-day training course called 'At A Loss' which seeks to enable support staff to assist adults who are facing or who have experienced bereavement.

Linda McEnhill

Linda McEnhill is Head of Family Support at St Nicholas Hospice in Bury St Edmunds. Linda is a social worker by training and has worked throughout her career in the fields of palliative care and learning disability.

Linda co-founded The National Network for the Palliative Care of People with Learning Disabilities with a small group of colleagues in November 1998. This organisation has members throughout Britain and seeks to promote and replicate good practice in the palliative care of people with learning disabilities. It provides (twice-yearly) national study days, regional group meetings and is a source of advice and information. It is a member of Help the Hospices Professional Associations group.

Belinda Paris

Belinda Paris has worked with Enable Scotland for the last twelve years and is currently Team Leader supporting three men with learning disabilities in their own home in the community and using a person centred approach to ensure that they are supported individually.

Claud Regnard, FRCP

Born in London of French parents, Claud studied medicine in Scotland, initially surgery and then General Practice. He later embarked on a career in palliative care and was Medical Director at St Oswald's Hospice for 11 years. He is now Consultant in Palliative Medicine at St Oswald's Hospice, the Freeman Hospital palliative care team (part of Newcastle City Hospitals NHS Trust), and the NHS Beacon palliative care in learning disabilities team in the Northgate & Prudhoe NHS Trust. He is also Honorary Lecturer in Pharmacological Sciences at Newcastle University.

In 1998 he was elected to the Fellowship of the Royal College of Physicians of London. He lectures and publishes widely, with particular interests in clinical decision making, symptom control, identifying distress in people with severe communication difficulties, setting up new services and creating accessible learning such as open learning and video conferencing.

Dr John Swinton

Dr. John Swinton is a senior lecturer in practical theology in the School of Divinity and Religious Studies at the University of Aberdeen. He has a background in learning disability nursing and community mental health chaplaincy and has researched extensively within the area of spirituality and human well being. Dr Swinton is currently involved in a nationwide research project funded by the Foundation for People with Learning Disabilities, which is seeking to explore the spiritual lives of people with learning disabilities. He is the author of various journal articles and books including 'A Space to Listen: Meeting the spiritual needs of people with learning disabilities; Spirituality in Mental Health Care: Rediscovering a Forgotten Dimension.'

Appendix 2

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Appendix 3

Contacts and resources

British Institute of Learning Disabilities
Campion House, Green Street, Kidderminster
Worcestershire, DY10 1JL
Telephone 01562 723010,
Email enquiries@bild.org.uk
www.bild.org.uk

Wide range of policy and research information and publications e.g. on cancer, communication, advocacy, and access to health services.

Common Knowledge
Killlearn Centre, 29 Shakespeare Street
Maryhill, Glasgow, G20 8TH
Telephone 0141 945 8046
E mail info@ckglasgow.org.uk
www.ckglasgow.org.uk

Common Knowledge is a learning partnership which is being developed to promote inclusion for people with a learning difficulty in Glasgow.

- At A Loss: a two day training course providing an introduction to supporting adults with learning difficulties through bereavement, 2000, SHS Trust, Edinburgh.
- What happens when someone dies? An e learning tool to support adults with learning difficulties through bereavement, SHS Trust, Edinburgh, 2003.
- Website information about the sexuality project and the project on loss and bereavement.

Down's Syndrome Scotland
158/160 Balgreen Road, Edinburgh, EH11 3AU
Telephone 0131 313 4225
Email info@dsscotland.org.uk
www.dsscotland.org.uk

A membership organisation working to improve the quality of life of people with Down's syndrome.

Combined book and cassette on bereavement 'Let's talk about death and funerals'. This can be viewed online or ordered from the organisation for a suggested small donation.

ENABLE

6th Floor, 7 Buchanan Street, Glasgow, G1 3HL
Telephone 0141 226 4541
www.enable.org.uk

FAIR

(Family Advice and Information Resource)
25/27 West Nicolson Street, Edinburgh, EH8 9DB
Telephone 0131 530 3322

FAIR has a sister organisation, the FAIR multimedia project, which offers advice, consultancy and expertise in producing accessible material for people with learning disabilities.

Foundation for People with Learning Disabilities
83 Victoria Street, London SW1H 0HW
Telephone 020 7802 0300
Email fpld@fpld.org.uk
www.learningdisabilities.org.uk

Website includes project information, research and training resources: 'Growing old with learning disabilities (GOLD)' and 'A Space to Listen' spirituality project.

Joint Future Unit

Community Care Division, 3 ER, St Andrews House, Regent Road
Edinburgh EH1 3DG
Fax 0131 244 5307
Email: jointfutureunit@scotland.gsi.gov.uk

MENCAP

123 Golden Lane, London EC1Y 0RT
Telephone 020 7696 5593
Helpline 0808 808 111
www.mencap.org.uk

Publications, including 'Your good health' a series of ten illustrated booklets can be purchased on-line from the bookshop.

National Network for the Palliative Care of People with Learning Disabilities
Linda McEnhill, Head of Family Support
St Nicholas Hospice, Macmillway Way, Hardwick Lane
Bury St Edmunds, Suffolk IP33 2QY
www.helpthehospices.org.uk/professional

[See box on page 27.](#)

Provision of telephone and email information is an emerging feature of the network. The network is building information, training and research resources.

NHS Education for Scotland
22 Queen Street, Edinburgh EH2 1NT
Telephone 0131 226 7371
Email: enquiries@nes.scot.nhs.uk
www.nes.scot.nhs.uk

Established as a Special Health Board in April 2002, building on the work of the National Board for Nursing, midwifery and Health Visiting and others, and extending its boundaries to cover all staff groups.

Holds lectures and events e.g. 'Beyond Consent: the concept in theory and practice'. Range of publications can also be downloaded from website.

NHS Health Scotland
Clifton House, Clifton Place, Glasgow G3 7LS
Telephone 0141 300 1010
Email info@phis.csa.scot.nhs.uk

The NHS Health Scotland website is under construction. In the meantime the HEBS and PHIS sites have useful information and links to specialist sub sites.

www.hebs.scot.nhs.uk
www.phis.scot.nhs.uk

NHS Health Scotland was established in April 2003 and merges the Health Education Board for Scotland (HEBS) and the Public Health Institute for Scotland (PHIS) to become the national agency for health education, promotion, information and advice.

NHS Quality Improvement Scotland
Elliott House, 8 - 10 Hillside Crescent, Edinburgh EH7 5EA
Telephone 0131 623 4300
or
Delta House
50 West Nile Street, Glasgow G1 2NP
Telephone 0141 225 6999
Email: comments@nhshealthquality.org
www.nhshealthquality.org

New agency established in January 2003 to support NHS Scotland with advice, guidance and support in improving the quality of the services it provides.

Website still under development. In the meantime look under Scottish Health on the Web, www.show.scot.nhs.uk/shas/publications for

- Learning disability assessment framework.
- Learning disability quality indicators - version for service users.
- Guidance notes for Trusts and NHS Boards.
- Guidance notes for service users and carers.

Royal College of Psychiatrists
17 Belgrave Square, London SW1X8PG
Telephone 020 7235 2351 ext 146
www.rcpsych.ac.uk

Order publications online at www.rcpsych.ac.uk/publications/bbw

'Books beyond words' are whole stories told in pictures. There are 26 titles in the series of books telling stories about important or difficult events that happen to people in their lives: they include help to overcome communication difficulties; mime and body language to communicate simple, explicit messages and supporting text and guidelines are given at the back of each book for relatives, supporters and professionals.

Scottish Consortium for Learning Disability
The Adelphi Centre, Room 16, 12 Commercial Road, Glasgow G5 0PQ
Telephone 0141 418 5420
Email administration@sclcd.co.uk
www.sclcd.org.uk

Publications soon to be available include 'Communication - Changing Focus' a training pack for trainers and senior managers who have responsibility for training support staff who work with people with learning disabilities.

Scottish Executive Health Department
St Andrews House, Regent Road, Edinburgh EH1 3DG
Telephone 0131 244 3076
www.scotland.gov.uk/health

Publications and consultation papers including 'The same as you?', 'Promoting health, supporting inclusion' and 'Partnership for Care' can be downloaded from Scottish Health on the Web (SHOW) www.show.scot.nhs.uk

This has a wide range of information including all the publications of the Scottish Health Advisory Service.

Scottish Human Services Trust
1a Washington Court, Washington Lane, Edinburgh EH11 2HA
Telephone 0131 538 7717
Email general@shstrust.org.uk
www.shstrust.org.uk

Wide range of information and publications on inclusion and health available in hard copy or which can be downloaded from the website. Including:

- Communities and Health: What will the outcomes be from greater partnership between people who use health services and the people who work in services?
- How individuals can make a difference: Partnerships between people who use health services and people who work in services.

Scottish Partnership for Palliative Care
1a Cambridge Street, Edinburgh EH1 2DY
Telephone 0131 229 0538
Email office@palliativecarescotland.org.uk
www.palliativecarescotland.org.uk

The Partnership works to ensure that people in Scotland who have progressive life threatening conditions, such as cancer, motor neurone disease or advanced heart failure, receive good palliative care.

St Columba's Hospice
Challenger Lodge, 15 Boswall Road, Edinburgh, EH5 3RW
Email med@stcolumbashospice.org.uk
www.stcolumbashospice.org

Independent unit in contract with Lothian Health and accepting patients from the Lothians and further afield.

Clinical services include:

- In patient unit.
- Community palliative care service.
- A day hospice.
- Medical domiciliary advisory service.
- Telephone advisory service for colleagues.
- Palliative care pharmacy advisory service for colleagues.

Also has a comprehensive education programme for medical students, medical practitioners, nurse and paramedical staff, and the clergy.

Appendix 4

The Adults with Incapacity (Scotland) Act 2000

This appendix includes extracts from Dr Rosaleen Beattie's article of June 2002 describing the Adults with Incapacity (Act) 2000 in terms of its impact on medical staff involved in palliative care.

The principles of the Act

The Adults with Incapacity (Scotland) Act 2000 contains new provisions authorising the doctor primarily responsible for the medical treatment of an incapable adult to do what is reasonable, to safeguard or promote the physical or mental health of that adult. The term "Best Interests" is replaced, in favour of for their 'Benefit'. This is in line with Article 6.1 of the Council of Europe's Convention on Human Rights and Biomedicine which states:

"An intervention may only be carried out on a person, who does not have the capacity to consent, for his or her direct benefit."¹

The legislation places great emphasis on enabling the adult with incapacity to exercise the greatest possible degree of decision-making and autonomy over his or her life. It acts alongside the common law power to provide treatment in an emergency to people who are unable to give consent, under the principle of necessity. Before carrying out any medical intervention, the doctor primarily responsible for an incapable adult's care must check that the proposed treatment complies with the principles of the Act.

The five core principles

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. (1.8.1)

Minimum Intervention

Where it is determined that an intervention in the affairs of an adult, under, or in pursuance, of the 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. (1.8.2)

Wishes and Feelings of the Adult

In determining if an intervention is to be made, and, if so, what intervention is to be made, account must be taken of the present and past wishes and feelings of the adult so far as can be ascertained by any means of communication, whether human, or by mechanical aid, as appropriate to that adult. (1.8.3)

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, so far as it is reasonable and practicable to do so, of the views of:

- the nearest relative and primary carer of the adult;
- any guardian, continuing attorney or welfare attorney of the adult who has powers relating to the proposed intervention;
- any person whom a sheriff has directed should be consulted;
- 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.

Encourage the Adult to Exercise Residual Capacity

Individuals unable to make decisions on medical treatment may be able to make decisions on other aspects of their care, and should be encouraged to do so. (1.8.5)

Assessment of capacity

The emphasis in the Act is on enhancing capacity, and not intervening unless incapacity is proven. For the purpose of the Act "Incapacity" means incapable of:

- acting, or
- making decisions, or
- communicating decisions, or
- understanding decisions, or
- retaining the memory of decisions

by reason of mental disorder, or inability to communicate because of physical disability.

In relation to any particular medical intervention, to assess capacity, the clinician must judge whether the adult:

- understands the nature and purpose of the proposed treatment;
- is aware of any alternatives;
- understands the likely risks and benefits;
- is aware that such information is of personal relevance to them;
- has memory abilities that allow the retention of information;
- is aware of their right to, and how to, refuse, as well as the consequences of refusal;
- is capable of making and communicating their choice;
- is expressing views consistent with their previous moral, cultural, family and experiential background;
- is making a choice which is free of coercion.

Capacity is task specific, and will apply to the ability to make a decision on the particular medical treatment proposed. Capacity is 'all or none' only for a single situation, not for all situations. Where the treatment or investigation is complex, or associated risks and side effects are likely to be severe, greater capacity is required in order to give a valid consent, and assessment needs to be more stringent.

There is no template or algorithm for assessing capacity, which has been validated for Scotland. The only guidelines are to be found in the Code of Practice and these supersede any previous guidance.

Requirement to consult

In addition to assessing capacity, the physician must consult widely to determine if the person has ever expressed their wishes relevant to the issue when greater capacity existed. Where a proxy with decision-making powers has been appointed, the doctor must consult and seek consent "if reasonable and practical".² This would at the very least, mean checking with family and carers if such an appointee existed. The requirement to consult and what this should entail is not clearly defined and the time required to identify and make contact will be weighed against the urgency of treatment in considering what is 'reasonable and practicable'.

Consult whom?

The Act provides that the following people should be consulted:

- Proxy with the power to consent: The Act makes new provisions for Proxy decision-making on behalf of Incapable Adults. A

relative, carer, or local authority representative may be appointed as Welfare Attorney, or Welfare Guardian with the power to consent on behalf of the incapable adult on matters, including medical treatment, relating to their welfare.

- Nearest relative (modified from the Mental Health (Scotland) Act 1984 (Sections 53-57); and irrespective of whether the relative was caring for the adult:

This will be the first person from a rigid list:

Spouse

Child

Father or mother

Brother or sister

Grandparent

Grandchild

Uncle or aunt

Niece or nephew

'Spouse' includes co-habitation for at least 6 months prior to admission and includes single sex relationships; relatives living abroad are excluded; separated spouses, and spouses who have deserted are excluded.

- Primary Carer - the person or organisation primarily engaged in caring for the adult
- Persons claiming an Interest - can include Mental Welfare Commission Public Guardian and Local Authority, but also anyone who claims to have an interest in the personal welfare of the adult, and will include, as well as close relatives, any person who has lived with, or cared for them, or about them, for a significant period. It specifically excludes those whose interest is that of an onlooker such as pressure groups, uninvolved neighbours, or those whose objectives go beyond the welfare of the individual adult.

Consultation, confidentiality and consent

In consulting other, doctors should not be giving confidential information. Rather they are seeking information from carers and others. If the doctor has decided there is incapacity, they consult others about the person and their capacity, not about the treatment. Consultees are not being asked to consent as a proxy, except where a welfare guardian has been appointed.

Medical Treatment Certificates

The doctor primarily responsible for the management of the patient must complete a Medical Treatment Certificate of Incapacity under Section 47 of the Act for the incapable adult, even if there is a proxy with the power to consent, such as a Guardian. 'Medical treatment' means any procedure designed to safeguard or promote the physical or mental health of the adult.

The certificate is treatment specific, and can give authority to treat for a maximum period of one year, renewable annually. Just as further consent must be sought from competent adults, if further procedures are considered necessary³ so too must a further assessment of capacity be documented for further interventions in incapable adults. However, treatment plans may be developed which will allow one certificate to cover several treatments.⁴

The certificate does not allow force or detention for the purpose of medical treatment unless immediately necessary, and only for as long as necessary; nor can it be used to justify an intervention which goes against a court decision.⁵ The provisions of the Mental Health (Scotland) Act 1984 are unchanged, as regards detention for the purpose of treating the mental illness.⁶

Exceptions are made for emergency treatment; where application for guardianship with treatment powers is being pursued; and for specifically excluded treatments.

The Act does not cover Advance Directives or the Withholding or Withdrawing of treatment. Existing criminal law is unchanged, and it remains a criminal offence, to unlawfully hasten or cause the death of another person. The authority under the Act is to provide medical treatment if it will benefit the adult, and "*nothing in the Act authorises acts or omissions which harm, or are intended to bring about or hasten the death of a patient*".⁷

Under Scots Law, euthanasia remains a criminal act.⁸ This does not, however, "impose a duty to provide futile treatment where the burden to the patient outweighs the clinical benefit".⁹

Footnotes

- ¹ Convention on Human Rights and Biomedicine, European Treaty Series/164,4.IV.1997, Article 6.1
- ² Adults with Incapacity (Scotland) Act 2000, Code of Practice for Persons Authorised to Carry Out Medical treatment or Research under Part 5 of the Act; SE/2002/April 2002, Annex 4, Section 2.68
- ³ General Medical Council, Seeking Patients' Consent: The Ethical Considerations; GMC, London Page 5
- ⁴ Adults with Incapacity (Scotland) Act 2000, Code of Practice for Persons Authorised to Carry Out Medical treatment or Research under Part 5 of the Act; SE/2002/April 2002, Annex 4
- ⁵ Note 4 *Supra* at Section 2.63-65
- ⁶ Note 4 *Supra* at Section 2.49-57
- ⁷ Note 4 *Supra* at Section 2.62
- ⁸ Note 4 *Supra* at Section 2.61-62
- ⁹ Note 4 *Supra* at Section 2.62