



'End of Life Matters' Report

Events held on 2nd May 2012 in Dumfries and 23rd May 2012 in Stranraer by DGVoice in Partnership with The Scottish Health Council, NHS Dumfries and Galloway and Dumfries and Galloway Council

1. Background to the event

In 2010 the Scottish Government published 'Living and Dying Well'¹, an NHS National Action Plan. NHS Dumfries and Galloway held 'Living and Dying Well Public Information Events' in October 2010 in Dumfries and Stranraer to raise awareness of end of life issues and the relevant services available to people in the region.

A number of DGVoice members who attended felt that this was an important topic for further discussion and debate and suggested that DGVoice should hold a number of events where disabled people, professionals and other interested agencies and people could come together to discuss the issues and make recommendations and help plan for future development of services and resources.

The event clearly demonstrates an appetite for end of life matters activities in our region

The role of the Scottish Health Council is to ensure effective involvement and engagement of patients, carers and communities in the delivery, design and redesign of local health services. The Scottish Health Council² in Dumfries and Galloway agreed to work in partnership with DGVoice and support the organisation to plan, organise and deliver End of Life Matters events across the region.

Planning and delivery involved many voluntary and statutory organisations working in partnership across traditional boundaries to hold an event where people felt comfortable and confident to contribute. A breakaway room and emotional and spiritual support was provided throughout the events for people who might be affected by any of the discussions. This was provided by staff of the Princess Royal Trust for Carers³ in Dumfries and Stranraer and the Newton Stewart Cancer Drop-In Centre⁴ in Stranraer.

¹ Living and Dying Well www.scotland.gov.uk/Publications/2008/10/01091608/0

² Scottish Health Council www.scottishhealthcouncil.org/

³ Princess Royal Trust for Carers www.carers.org/

⁴ Stranraer and Newton Stewart Cancer Drop In Centres www.scdic.org/services.php

It was agreed to hold events in Dumfries and Stranraer to ensure as many people as possible could attend. We wished to provide maximum opportunity for a diverse audience to participate in discussions and share ideas in a supportive environment. We therefore ensured that 50% of delegates were non-professional and there was a maximum attendance of 50 people at each event.

There were five round table discussions with two or three facilitators with specialist knowledge at each. They moved from table to table so that all delegates had an opportunity discuss all topics (see appendix 1).

The event was massively oversubscribed with many more requests for places than it was possible to provide. It had been hoped to accommodate this with a further event, however financial and staff resources did not allow this to happen and organisers wrote to potential delegates to explain this and advise that they would be provided with the report and kept up to date with developments.

2. The aim of the events

People will be able to make informed end of life decisions and contribute to the future development of good end of life care and support provision in Dumfries and Galloway.

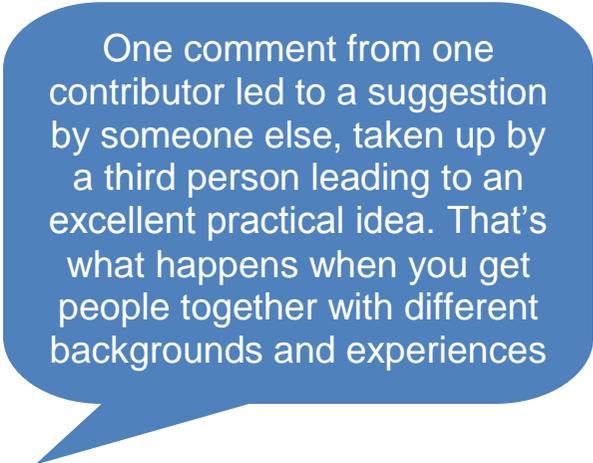
3. Expected outcomes

People will have up-to-date information about:

- Financial planning
- Employment and welfare benefits
- End of life care and treatment choices
- Housing, aids and adaptations
- Carer information and support



Who would have thought that discussing end of life could be so very interesting fun and uplifting?

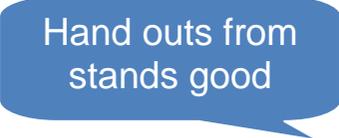


One comment from one contributor led to a suggestion by someone else, taken up by a third person leading to an excellent practical idea. That's what happens when you get people together with different backgrounds and experiences

- Rights and responsibilities, national and local policy and equality issues
- Bereavement
- Access to information
- Spiritual care

Local and regional strengths and gaps in end of life services will be identified.

People will influence the regional development of key national and local end of life strategies.



Hand outs from
stands good

4. Programme for the day

On arrival delegates were given an information pack providing information about the programme and the arrangements to support anyone who found the presentations or discussions upsetting. Stands were available all day for people to obtain further help and information from various organisations (see appendix 2 for list of organisations).

Opening presentations

Jeff Ace, Chief Executive, NHS Dumfries and Galloway, opened the event in Dumfries:

“NHS Dumfries and Galloway welcomed the opportunity afforded by DGVoice to participate in the End Of Life Matters Seminars and for our NHS representatives to learn at first hand the key issues of concern and interest expressed by the broad range of individuals, carers and service users who took part along with partner organisations' representatives. It was especially important for us to hear the views of individuals within the discussion groups and to take away from each of the events specific actions which I believe can enhance the patient and carer's experience of our services in the future.

As Chief Executive, I am firmly committed to ensuring that the key learning points deriving from both events are put into practice to ensure that patients' and carers' needs are at the forefront of our future planning and service delivery.

I commend DGVoice for organising and facilitating what was an impressive learning opportunity for the statutory agencies involved."

Hazel Borland, Director of Nursing, NHS Dumfries and Galloway, opened the event in Stranraer.

Professor David Clark, Director of School of Interdisciplinary Studies, University of Glasgow delivered the opening presentations and told delegates:

"The last half century has seen a growing recognition that 'end of life matters' are hugely important. Hospice and palliative care were once the interests of a small minority of people who largely operated outside the health care system, but today policies on end of life care are becoming much more central to the thinking of government and the caring agencies.

Chance to
raise this
taboo subject

All of us will have some notion (if we stop to think about it) of how we might like to die. There is quite a bit of agreement about what makes for a 'good death' - freedom from pain, the involvement of understanding carers, the support of family and friends, the ability to remain at home as long as possible, perhaps a measure of choice and control over the situation.

But just how this is to be achieved is less clear. Do we have the 'right' to die in the manner and time of our choosing? How can we achieve a 'good enough death' for everyone, rather than special provision for those with the right postcode or diagnosis?

In Dumfries and Galloway there are some 1850 deaths each year. In this region we face special challenges in bringing services to our rural population and our dispersed communities. About 23% of people die at home. Others die in hospitals of various types and a growing number in care homes.

What do we know about the quality of dying in our region? What initiatives might improve things? Who should be involved?

These are some of the challenging questions we are facing in these meetings. I am involved with a group of researchers interested in similar questions. Together, by combining research with community activism, we may be able to come up with the answers. At the end of life how can we get care right for everyone - because when it comes to this point, there is 'no second chance'?"

Amy Wright, DGVoice Member, then gave a presentation about her experience as a disabled young person caring for her father during his final illness. It is reprinted here in full.

“My name is Amy Victoria Wright and I was born on 17th December 1991. I’ve been through more than most people my age. At four years old I had major heart surgery and without that surgery I might not have been speaking to you today. To add to that, I was diagnosed with Developmental Dyspraxia. This is a recognised disability. It is “an impairment of immaturity of the organisation of movement”, meaning the brain can’t process information correctly therefore causing signals from the brain to be misinterpreted. For me in particular I have a poor physical ability, poor balance, poor hand eye co-ordination, poor self esteem and low confidence. It affects me every day and simple tasks can prove hard for me. There is no cure. I’ve just got to learn to live with it.

The young girl who spoke first touched my heart I thought she was so brave to speak in front of everyone with all she had been through

Sadly on 19th January 2000 my mum Edna passed away, I was eight years old. Friction within the family started and Dad suffered with depression so I didn’t live with him permanently. My Dad recovered and got back on his feet so I moved back home.

After a routine dentist appointment Dad went through a series of tests and scans. Finally he went to Carlisle Infirmary’s Head and Neck Oncology Department and was diagnosed with mouth cancer in spring 2003, at the time I was eleven years old. Plus I had to learn a whole new language. In the summer holidays Dad went in for

four or five weeks of radiotherapy and he also had an operation. In December problems occurred as a result of the operation so Dad went back into hospital for a skin flap. I can remember that Dad was feeding through a tube in his nose and he found the instructions for the machine and managed to get the feed to go through faster. After that we all thought that Dad was better, he was playing snooker and taking part in quizzes. We went on holiday. However...

In 2009 Dad was diagnosed with cancer of the larynx. In December he had a laryngectomy. His larynx was removed and he breathed through a stoma. It was a big operation and Dad's recovery was slow but steady. Also at the same time I just started my first ever job at Tesco in Annan, which was for me a really important step to take. However it was difficult for my colleagues to see what I was going through and it was even harder to co-ordinate visiting Dad with my shifts. When I visited Dad on my 18th birthday he could talk to me. What made it special was the nurses at Carlisle gave me a birthday card and somehow managed to get me my present of an iPod from my Dad. Again we thought Dad was recovering but in spring of 2010 we were given the news the cancer had come back and was terminal, nothing could be done. That's when Dad changed but that's also when I changed. Dad was prescribed numerous medications which I helped to manage. The staff at Rose Street Pharmacy, Annan were very understanding especially when it came to ordering medicine. Dad had a medicine chart with what medicines he had and at what times. He was very particular with his times – it had to be on the hour. At that point I had only a gap of about two hours each day when I could go out to meet friends and be a teenager. As Dad was unable to eat he was very weak and couldn't always support his own weight. When I was at work I would always worry about him falling over. This was such a difficult time for me.

Then one weekend it all changed. Dad became worse. He kept falling over all the time and wouldn't respond to either me or my Auntie talking to him. So with the help of the district nurse who came on the Monday morning it was decided that Dad would go into the Alexandra Unit at DGRI. One issue was that Dad had to first go to general ward, so the nurses weren't specialised cancer nurses so didn't really know what they were dealing with. But for me the scariest thing I had to do was to give Dad his morphine through his tube in a room of medical professionals. Dr Martin saw Dad and quickly decided that Dad needed to go to the Alexandra Unit. On Wednesday 3rd November 2010 my Auntie and I were asked to make our way to the hospital in the morning. We had spent most of the day there just chatting away about the memories we had of Dad and

wondering what he would say about some of them if he could hear us. The staff were lovely and got us lunch and tea. Then about 6.15pm Dad peacefully passed away. I was obviously upset but I already knew that this day was going to happen; the staff in the Alexandra Unit were caring and thoughtful.

I could only write this speech in small parts as I kept getting upset. I would like to say a heartfelt thank you to all the medical professionals at Carlisle, Dumfries and Annan who helped me, my Dad and my family.”

Round table discussions

John Glover, Head of Communications, NHS Dumfries and Galloway, invited delegates to participate in 5 facilitated round table discussions.

The discussions provided participants opportunity to share thoughts and gain information on a variety of topics related to end of life matters. They were in the form of round table discussions (world cafe⁵ style) with approximately 10 people at a table.

The table discussion topics were:

- **End of Life care and treatment options**
- **Bereavement and spiritual care matters and carer support**

Well organised and flowed smoothly which made participating easy and more enjoyable, the value of telling and hearing people's stories was highlighted

Exceeded expectations
- Wide ranging and open minded brilliant range of contributors at tables

Good range of topics associated with end of life care

⁵ World Café is a participative process which enables people to have creative conversations while sitting cafe-style around small tables. Paper table mats are often used so that the ideas and issues which emerge from the conversations can be recorded

- **Housing, aids, adaptations and telecare⁶ options**
- **Financial planning, employment and benefits**
- **Shaping the future of care in Dumfries and Galloway**

Each table included a range of participants who were either a member of the public, voluntary organisations or a professional. The facilitator⁷ teams, made up of two or three people, moved from table to table so that every person attending had an opportunity to contribute to every topic.

In view of the nature of the subject matter, participants were assured that there was no need to share personal experiences but that such contributions would be welcome. The scene was set so that all would feel able to contribute their thoughts to the discussions. Quiet rooms with professional listening support were available for anyone who felt the need.

Tremendous discussion very well organised, facilitators moved round so we at the group could get to know each other

Each round table discussion lasted 40 minutes. Facilitators noted three main issues and challenges from each table and the top three ways to address these. Participants were also provided with individual feedback 'table mats' to jot down any individual points and put in the feedback box.

Table discussion facilitator feedback

There was a huge amount of feedback and discussion. Through the facilitators' top 3 points and participants' table mat feedback, this section will highlight the main points and themes, including issues, challenges and ways to overcome these challenges.

Staying at one table with facilitators moving made for a more productive experience

⁶ Telecare is the term for offering remote care of elderly and physically less able people, providing the care and reassurance needed to allow them to remain living in their own homes

⁷ Facilitator - Someone who helps a group of people understand their common objectives and assists them to plan to achieve them without taking a particular position in the discussion

Discussions helpful-
emotional at times-
some stimulating
debates

Accommodation for families to stay
when the new hospital is being built
could this be considered especially
for people from Stranraer; 75 miles
away, no transport - late at night.
People with no other family just lost
someone dear to them needs support

What people said...

We heard good stories and bad stories and we heard some good ideas to improve existing services. People were enthused in spite of the long days.

Buzzy
atmosphere –
food for thought

End of Life care and treatment

Issues and Challenges

- People with advanced dementia⁸ should have someone with them all the time
- DNACPR⁹ (Do not resuscitate) and choice of where you die is critical
- Choice and control
- Lack of communication and information
- End of Life Care Plan¹⁰
- Lack of compassion - isolation
- Training and attitudes
- Advance directive¹¹ document
- Communicate honestly and treat with dignity
- Respite care¹²
- Spiritual / psychological health
- Support
- Choosing the right people to be nurses
- Lack of compassion in the earlier stages of dying
- Support for family and friends
- No follow up for long term conditions
- Person not told he was dying
- Treatment needs to be immediate
- Joined up working
- Broaden expectation of high standards of care beyond cancer
- People become more ill because of distance to be travelled
- Accommodation for family
- Patient transport and equipment - lack of dignity in transport
- Advocacy - advance directive
- Pain relief
- Rehabilitation¹⁵ after stroke and other long term conditions¹⁶
- Discussion of approaching death

⁸ Dementia: A set of symptoms that include loss of memory, mood changes, and problems with communication and reasoning

⁹ DNACPR: Do not attempt Cardio-Pulmonary Resuscitation

¹⁰ End of Life Care Plan: All people approaching the end of life need to have their needs assessed, their wishes and preferences discussed and an agreed set of actions reflecting the choices they make about their care recorded in a care plan

¹¹ Advance Directive: A set of written instructions that a person gives that specify what actions should be taken for their health if they are no longer able to make decisions due to illness or incapacity

¹² Respite Care: The provision of short-term, temporary relief to those who are caring for family members who might otherwise require permanent placement in a facility outside the home

<ul style="list-style-type: none"> • Distinguish between palliative care¹³ / terminal care¹⁴ • Timing of conversation about end of life care plan 	<ul style="list-style-type: none"> • Choices - reduced because of issues of numbers and resources • Continuity of care
<p>Ways to overcome these challenges</p> <ul style="list-style-type: none"> • Raise awareness and discuss • Advance Care Plans • Everyone in care home to be offered support to write an Advance Directive • Clinical Nurse Specialist for older people • Put DNACPR form in bottle with medication • Advocates¹⁷ to act on advance care plan • Volunteer to be available as bedside companion • Workshop on writing advance directives 	

Looking at **End of Life Care and Treatment**, the top concern was the ability to have choice and control over care, and to have advance directives which were easily available to those who needed to know the person's wishes.

There was concern over lack of suitable transport for both patients and their loved ones. Coupled with this were thoughts about accommodation for family coming from the far west and east of the region.

¹⁵ Rehabilitation: To help someone return to normal life

¹⁶ Long Term Condition: A condition that cannot be cured but can be managed through medication and/or therapy.

¹³ Palliative Care: It is appropriate for patients in all disease stages, including those undergoing treatment for curable illnesses and those living with chronic diseases, as well as patients who are nearing the end of life

¹⁴ Terminal Care: Care provided for someone judged to be in the last phase of their life

¹⁷ Advocate: somebody who acts on behalf of another

There was enthusiasm for the concept of writing advance directives with ideas about popularising the concept of taking responsibility for ensuring your wishes about your end of life care are known by your family, your medical attendants, your social worker, your care provider, your advocate, your lawyer – and anyone else who needs to know. A supporter or advocate to ensure this happens is invaluable.

Advance care planning was also identified as important. It should involve adequate and appropriate pain relief; should be compassionate and enhance dignity; should include unpaid carer¹⁸ support and respite care. Attention should be paid to seamless continuity of care.

The value of agencies working closely and sharing information was discussed many times. The importance of communication and information was highlighted in addressing the isolation and confusion often felt by people entering the end phase of their life. In particular the distinction between palliative and terminal care was not understood.

Bereavement¹⁹, spiritual care and carer support

Pastoral spiritual care is really important for people who are dying. Whether the patient is supported by a family or not they should receive 'pastoral' support – not 'religious' initially but someone who can sympathetically seek out the dying persons needs and wishes and if possible act on them e.g. providing religious comfort, saying their goodbyes to friends/loved ones

Clearly much still to be done on spiritual care - understanding and differentiating from religion

Signposting to support networks

¹⁸ Unpaid carer: Spouse, family member, close friend

¹⁹ Bereavement: Refers to the state of loss, and grief as the reaction to loss

Issues and Challenges

- Compassion, dignity and respect needed
- Understanding and respecting spirituality of individual
- Asking for help for oneself
- Difficulty of filling in forms - they are horrendous, even for articulate people
- Support for non-religious spirituality, or not if one does not want it
- Bereavement and children's needs important
- More talk about dying before death
- Carer guilt - isolation
- Transition from young carer status to carer status
- Lack of support for professionals
- Lack of 'listening', compassion
- Continuing support
- Support for staff dealing with bereavement within their caseloads
- People realising they are a carer and being defined in that role
- Finding information about bereavement support and about the bereavement process itself and losses before death
- More resources for children who are bereaved
- Information - lack of where to find info including bereavement
- Funding of Cruse²⁰
- Support from church and community not as strong
- Support for family carers so that they can just be a husband/wife
- Carers role difficult – little/no support for carers
- Support for those bereaved not there
- Bereavement: no normal time -could be years
- Little support for male carers
- Lack of mechanism for referral to carer support
- People becoming reliant on professionals during bereavement
- Not talking about death
- Doctor did not seem to appreciate daughter's input
- Families don't know where to turn
- Not having all answers, understanding what the individual needs
- Different people have different religions
- Finding out information, sharing information with family members
- It is 'not done' to show emotion.

²⁰ Cruse: www.crusebereavementcare.org.uk/

National charity set up to offer free, confidential help to bereaved people

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| <ul style="list-style-type: none"> • General societal lack of active support for bereaved - 'get over it' culture • Talking about end of life matters with those closest to us • Registration of carer on GP's notes now they are computerised | <ul style="list-style-type: none"> • Exclusion of children • Finding support • Lack of training • Spirituality is not often discussed • No mechanism for support in the community when there is a sudden death |
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Ways to overcome these challenges

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| <ul style="list-style-type: none"> • Anticipatory planning - Advance Directive and be aware of where this is kept and who has one • A one-stop shop²¹ for information about practical matters and find 'talking support' • An advocate for a carer for the family, particularly for form filling! • Financial responses • Bereavement - wider than the NHS • Lack of bereavement services - more money • For GPs to allocate double appointments to carers and bereaved • Sharing stories | <ul style="list-style-type: none"> • Better information signposts • Cruse info and support more available • Link person for info about specific charities • Work as part of a team. More info from GP • Do not call patients 'patients'. They are people. • Being positive • More training needed for care workers • More training in supporting carers, bereaved families • Set up a stroke group (by stroke sufferer) |
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It was made quite clear that **spiritual care around bereavement and support for the emotional needs of family carers** was very important. Good spiritual and emotional health gives a foundation to the promotion of good physical health. However, people do not talk easily about death and dying and how they feel about it. The challenge is to find ways to make this easier and more acceptable so people feel less isolated in their grief, or when they are dying.

²¹ One stop shop: A place where various requirements can be met in one place

It was acknowledged that Cruse does great work in supporting those bereaved and adequate funding must be made available for them to continue.

It was felt that more attention needs to be given to treating people with compassion, dignity and respect and that there should be specific staff training around these issues.

It was agreed that more attention should be paid to those about to be bereaved and that care and support should be available at a much earlier stage in the process.

These events were excellent opportunities for sharing information. There are many instances of good practice, of good ideas, out there unknown to the majority. We need to devise a way of pulling everything together into a good end of life strategy. An example is the bereavement packs available in the Alexandra Unit. These give contact details of organisations and agencies which may be of assistance to a bereaved person. These should surely be available to everyone who needs them.

The value of impairment specific support groups was acknowledged where people could share experiences, treatments and coping strategies.

It was agreed that GPs have a vital role to play in end of life matters. They should allow extra consulting time for discussion and support.

Information and signposting should be easily accessible in the same place.

More speedy access to equipment. The process between clients and social worker should be faster

It certainly highlighted the gaps in provision for people who are at end of life

Earlier intervention required. Referral before discharge from hospital, e.g. demonstration unit in a large warehouse so people can try before they buy

Housing, aids, adaptations and telecare

Issues and Challenges

- Lack of communication
- Time delay in referrals
- Best use of assessment period
- Shortage of sheltered accommodation options
- Problems with definitions of "community care"
- New build or adapting properties to be fit for purpose
- How services accessed
- How to build in 'sheltered' options into care options
- How to address future needs now
- Time for forward planning
- Communication systems
- Connecting the services
- Sustaining quality and adapting to changing need
- Red tape
- How to manage and coordinate calls and who does it
- Discharge planning (out Friday - back Monday)
- How to make agencies work together
- Not client centered
- How to include the community in identifying issues of care
- Adapting current houses to people's needs
- Making people work together and getting information

Ways to overcome these challenges

- Demonstration unit for Aids and Adaptations with training opportunities
- Design overall care options appropriate to the assessment
- Social Work assessment to include wider community issues
- Improve communications between services - community hubs
- Promotion and sign posting
- Resource planning
- Funding and creation of demo unit, change fund?
- Equal access - a universal service, Irrespective of tenure
- Speed of access (especially End of Life); alert GP early
- Single coordinator/enable - multi agency
- Make referrals quicker and easier and appropriate to individuals
- Make policy change across all sectors to include aids and adaptations
- Early intervention (flag up)
- First response (rapid response)
- Better bed management
- Appropriate training and staffing - with move to community care
- Early intervention to identify need
- Rapid response team
- Cross agency direction from top of organisations
- Streamline referrals
- Passport document for services
- Register of adapted social housing
- 24 hour access available to all
- One stop shop for relevant service
- Early intervention with discharge planning on admission
- Continuous case management/discharge planning
- Training / GP involvement / District Nurse

The facilitators found that at the end of life, there are huge frustrations around delay in provision of sometimes the most simple of aids – a Zimmer frame²², a bed, a ramp. Timely provision can make all the difference

²² Zimmer frame: A walker or walking frame is a tool for disabled or elderly people who need additional support to maintain balance or stability while walking

between a 'good death' at home where a person wants to be, and a less than ideal death in hospital because that is not where the person wishes to end their days.

There are delays in referral, delays caused by lack of communication and delays caused by poor planning. It should be possible for a person to go home to die at any hour of any day and not be constrained by the working hours of the agencies involved. At present the system is agency centred rather than person centred.

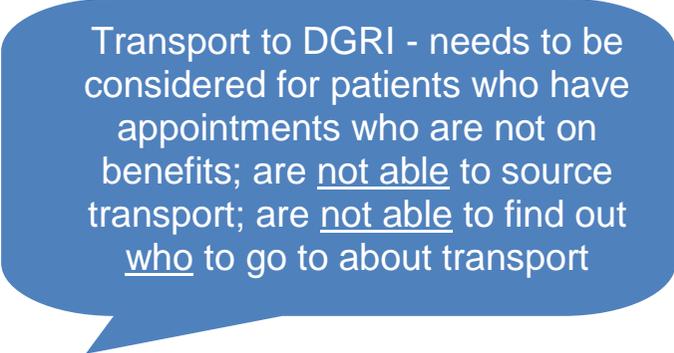
Urgent priority must be given to reviewing access to aids and adaptations particularly in relation to people wishing to go home from the terminal care unit and those with a short term diagnosis. There is no time to wait for the arrival of a ramp, a chair or a Zimmer. To this end, better interagency working, aided by a rapid response team, was a suggestion arising from discussions.

Discharge planning, involving all agencies, should begin as soon as a person is admitted to hospital. Ways need to be found to speed up referral response times.

An innovative idea to come out of discussions was to use 'Change Fund'²³ funding to establish a mobile demonstration unit of aids and adaptations.



Single point of contact for advice and support



Transport to DGRI - needs to be considered for patients who have appointments who are not on benefits; are not able to source transport; are not able to find out who to go to about transport

²³ Change fund: Reshaping Care Change Fund announced in the Scottish Government's draft budget will help the shift to preventative public services and recognises the key contribution that the third sector will make to this

Financial planning, employment and benefits

Issues and Challenges

- Stress in understanding process
- Entitlements for young people
- Lack of competency and skills/literacy for completing forms
- Lack of information/poor communication about changes to benefit system
- Inequalities in provision of services - rurality issues²⁴
- Support for employees required, e.g. welfare policies/employer attitudes
- Access to information on benefits at time of crisis
- Support for individuals to plan/prepare
- Unbiased advice is required
- Process to identify personal budgets (varied) and differences across age groups
- Difficulty completing benefit forms/concerns about new benefit regime
- Changes to benefit system - huge challenges
- Funerals - planning ahead, costs, lack of choice in plots
- Information sharing and sign posting- passage from professional to public
- Financial planning not taught at school
- Transport – co-ordination of Transport
- NHS D&G²⁵ – More sensitive to Hospital appointments
- Lack of information on Benefits / prioritising for the future
- Pension contribution – capped!
- Assistance for older people in retirement
- Hard to reach groups – information and support
- Affordability - paying for a Power of Attorney²⁶ and wills
- Family conflict around finance (not clear on the process / costs)
- Blue Badge²⁷ process needs improved in D&G
- Benefits information literature – Language used is too confusing
- Impact of Benefits Review
- Future Costs

²⁴ Rurality issues: Dealing with things special to the country rather than the town or city

²⁵ National Health Service Dumfries and Galloway

²⁶ Power of Attorney: The legal authority to act for another person in legal and business matters

²⁷ Blue Badge: Disabled person's parking permit

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| <ul style="list-style-type: none"> • Care - cultural differences in how we care for people, role of family • Social isolation • Lack of technological skills • Mobility / geographical issues in accessing support and information • Taxation issues • Who is the right person to approach? • Challenge of completing benefit forms • Lack of consistent unbiased information • Employer support in relation to staff welfare policies at times of crisis • Language barriers in completing forms • How do those on low incomes pre plan? Jobs, poverty, rurality, transport | <ul style="list-style-type: none"> • Require more informed information on the roles of attorney issue • Professionals remit to inform people more clearly • What are the Legal issues - awareness in society as a whole • No access to relevant information for those in need • Awareness of the role of Power of Attorney and cost • Assessing needs for Benefit support – structure needs improved • Affordability - Burdens to families • There needs to be increased text size on formats and Braille available if required • Confusing formats • Clarity on how appeals are conducted and assessed is required |
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Ways to overcome these challenges

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| <ul style="list-style-type: none"> • Use of volunteers to assist with signposting • Face to face contacts - home assessment visits • Benefit referral at discharge • Raise communication standards • Age Concern Life Booklet²⁸ to be made available electronically and to carers and care settings | <ul style="list-style-type: none"> • Develop local directories that are easily accessible to the public • Need session workshops on wills and Power of Attorney • Clear pathways on paying for the future |
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²⁸ Age Concern Life Booklet: www.ageuk.org.uk/scotland/home-and-care/home-safety-and-security/lifebook

a free booklet where you write important and useful information about your life, from who insures your car to where you put the TV licence

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| <ul style="list-style-type: none"> • Increase awareness of issues for employers • Establish 'status crisis unit' for those about to retire/mid life • Develop joint work support groups (partnership work) in a variety of Venues (Community Centres, Public meeting areas), to promote awareness and offer advice to those hard to reach • Develop education on end of life planning as part of a core set of life skills • Those engaged with clients/patients to be more informed and able to signpost • More resources to support Benefits Maximisation Team²⁹ and DGCAS³⁰ • Improved sharing of information/awareness raising for employers • Work with Multi-cultural Association to support overseas workers | <ul style="list-style-type: none"> • Develop improved access to information - where and how we access it. Signposting by agencies • Better and improved partnership work between services • State to provide a safety net on pensions • Re-education opportunity for people for end of life • Affordable system that's fair to all (power of attorney) • Central point of contact (drop in centre at DGRI³¹) • Incorporate improved travel structures • Early planning - funeral planning/care - choices • Review of lifestyles, early intervention. To assist people to prepare for later life • More Media awareness (coverage of Benefits Availability) |
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There are particular problems for many people in Dumfries and Galloway. In an area where many families are on very low incomes and with high unemployment, planning for funeral costs and extra costs incurred around the end of life, is well nigh impossible. This adds to the stress already present caused by the mass of confusing forms to be completed.

²⁹ Benefits Maximisation Team: This service is part of Dumfries and Galloway Council and can help to ensure access to all benefits and services that a person is entitled to

³⁰ Dumfries and Galloway Citizens Advice Services

³¹ DGRI: Dumfries and Galloway Royal Infirmary

People are being asked to attend for Work Capability Assessments³² and being judged fit for work and benefits stopped even when their condition is judged to be terminal. They then have to cope with the stress of further reduced income and an unclear and lengthy appeals process.

The Benefits Maximisation team can do invaluable work with people at this stage in their lives. It was felt that this team should be given adequate resources to fulfil and perhaps expand their role.

Other solutions discussed were ways to encourage people to plan ahead and workshops were suggested to cover writing wills and arranging powers of attorney. The establishment of a 'status crisis unit' was another excellent idea to emerge from the discussions.

Delivering care close to home

Good- The optimistic views of how we can change services for the future

Listening to everyone and discussing all the issues about end of life matters has been very important as we have all different stories and opinions to discuss and everyone has to know how we all feel

Would like to see a discussion document and a booklet which listed organisations and what they do

We need more joint events with Health and Social Work to develop some of the issues discussed where appropriate

³² Work Capability Assessment The *Work Capability Assessment (WCA)* was introduced in October 2008 to assess entitlement to Employment and Support Allowance (ESA)

Shaping the future of care in Dumfries and Galloway

Issues and Challenges

- Children and teenagers - die in adult wards - facilities
- Attitudes to death/dying - support
- Lack of honesty - not being able to talk about death and dying
- How do we capture people's wishes in relation to end of life care
- Choices - how do we communicate available choices; how do people express their choices
- Is it appropriate that 'Putting You First' focuses on care at home in view of lack of transport and rurality of the region
- Do people want to die at home? - What services are available?
- How can Local Authority/NHS/3rd Sector join up?
- Social Work - once patients placed in care sector - detached - how do we communicate/support
- Relatives/carers - possible need for pre-bereavement support or counseling
- Only 2 Palliative beds in Galloway Community hospital - specialist resources - ↓role of cottage hospital
- Travel to Dumfries to support family members in hospital. Burden of cost of travel and disruption to family. Also travel in West, e.g., Isle of Whithorn
- Emotional support
- Rural care - providing care in rural/isolated places medical/social
- Additional issues: Benefits systems (eg DS1500³³ - this needs to be streamlined)
- Carer recognition and support
- Language and terminology
- Lack of overnight support/cover
- Giving people info at the right time
- Planning for End of Life care needs to be started early
- Equity of access to Palliative Care beds not just for cancer patients

³³ This is a form, completed by a medical professional, which enables someone who is terminally ill to claim Disability Living Allowance (DLA) or Attendance Allowance (AA) under what the DWP calls "Special Rules."

- Uncertainty around when and where end of life discussions need to take place
- Lack of continuity in home care staff/services in community.
- lack of information around Self Directed Support and how to access it
- Care in Community/home and out of hospital as soon as possible
- Lack of general medicine care Out Of Hours - NHS 24 – poor connection/response
- lack of consistency in carers and services from agencies
- How do we help families to talk if they want to
- Appropriateness of nursing staff behaviour/perception
- Need to speed up communication between teams at end of life - getting consensus and agreement from the wider team
- How do we deliver good care, eg hospice standard and support for those left behind if needed
- How do we help people with dementia and capture their wishes
- Rurality/transport.
- How do we capture the views of all / broad spectrum of public opinion - lead to coproduction/co-creation of services etc. Less of being done to - do with
- Are people/carers trained and have appropriate time to undertake duties?
- Impact of having care delivered in Dumfries for families in the West of the region - travel, childcare, cost, work/life balance. How do we get the care right?
- Finding local solutions to fit the needs of the local population. Isolation of people from the west and east of the region cared for in Dumfries not having visitors
- Funding local services. Finding the time to provide person-centred care
- What is the role of community in supporting families
- Who is relevant person to provide information
- How is information accessed by people who may not be computer literate, or have barriers such as poor sight/hearing
- Design DGRI/Care Homes that have quiet/reflective spaces
- Give people at end of life choice and control over their life.
- GP contracts - 24 hour medical support
- People to provide social care overnight
- Should be compassion at the centre of care

Ways to overcome these challenges

- Simple information pack outlining role of staff and options for care and support
- "BIG Society" approach - balanced between professionalisation, doing in partnership with 3rd sector and communities - spiritual life/discover and articulate who you are and what you need
- Information from NHS/Local Authority to population on what is available and how to access
- Recognition of different skill sets and how they integrate together
- Role of Case Manager
- Provision of pre bereavement support/counselling - Cruse, BIG SOCIETY
- Develop role of professionals - must be sympathetic and not over burdened
- Recognise opportunities for the difficult conversations
- Develop strategies for significant cultural change in both the general population and services
- Use the Putting You First Change Fund
- Use cottage hospitals
- Direct Payments/Personalisation supports consistency of care and greater control: HOLISTIC CARE
- Care co-ordination role while patient in hospital in order to support patients return to local community/home or care home.
- Consistency of support / service directed by person themselves
- Hospice at home service - rurality of Dumfries and Galloway
- Network of friends supporting one another - linking with Local Authority/NHS - especially at end of life. Working together, mutual support
- Link awareness raising to more general life experiences (state pension, making wills, including earlier life opportunities, e.g. donor card approach)
- Additional Palliative Care beds in west of region. Palliative Care bed in Newton Stewart cottage hospital. Developing community support and proximity to family/friends reducing isolation
- Possible care at own home or in care home. Discharge planning to include personal planning of care. Quick response of services
- Travel costs to support patients who need to be in Dumfries and Galloway Royal Infirmary.
- Rapid access to child care, kinship care/payments.
- Build death and dying elements into professional training/ongoing professional development
- On call nurse system, eg Renfrewshire Macmillan nurse pilot. In combination with flexible system of carers
- Local solutions - rather than focusing care/services around a central centre of excellence

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| <ul style="list-style-type: none"> • Joined up working with Local Authority/NHS and 3rd sector. • Access to SHAWL³⁴ group in Stranraer for Reikki etc to manage stress and support • Social work presence in hospital - focus on needs of patient and early discharge planning and family support • Communicate with person and information sharing across professionals and others • More information for general public - more awareness • Clearer, better information for the person and family re diagnosis/options | <ul style="list-style-type: none"> • Pilot in Stranraer re buddy system for Dementia sufferers • Honest, timely communication from medical staff. • Model of information giving with 3rd sector providers to signpost families and carers to relevant services • Building relationships with media to develop community profile in local media - with community groups. Rotation charity page to advertise groups and meeting dates |
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There was a great deal of crossover in the issues discussed in **Shaping the Future of Care in Dumfries and Galloway** and the discussion in other groups. People raised a wide range of issues and challenges and how these might be overcome but there were some that were raised again and again.

There are lots of challenges about communication including ensuring that communication is at the right time and place, that the approach and language works for the person and, if required, that support is available for what can be very difficult conversations. Supporting people to make their wishes known, advance directives and advance care planning and where required provide support including advocates to support this. There are issues about communication between teams supporting the person. On a wider basis there were challenges around capturing a range of views from a broad range of people and working together on the future shape of services.

³⁴ SHAWL Group (Supporting Holistic, Arts and Wellbeing Locally) This group have several trained volunteers who offer Holistic therapies such as Reiki, Tai Chi for Health, Indian Head Massage and Mindfulness. The group meet on Tuesdays at the Coronation Day Centre, Whitson Avenue, Stranraer from 10.30 until 12.30

There are significant challenges about the availability of information about what services are available, how to gain access to them and how they work. This needs a more proactive approach to developing and getting information out to people. Honest, timely, simple information is required. Signposting people to relevant information and services, making use of local media, linking the provision of information to natural life stages (state pension, making wills...) might be ways of helping people know what is available and how to access services and support.

The rural nature of Dumfries and Galloway brings challenges for getting people and services into local communities but also issues for people being cared for in settings away from home. This can bring isolation for the person at such a difficult time in their lives. For carers this has related burdens around travel time, the ever increasing costs of travel and disruption to family life. There is a need for the development of local solutions and a recognition of and support for people around the challenges of distance and travel.

There are issues about the availability of services and resources and at times the quality of services. There is a lack of specialist services especially for children and young people. A lack of overnight support is an issue for many people including lack of social care and input from nurses and GPs. The design of hospital and care home space to allow for privacy was an issue. The quality of care, the time allowed for staff to provide care and the continuity of care are all of concern.

People want to see a shift from service centred care to person centred care with the person having choice and control but there are concerns about how we deliver this locally. There are specific concerns about a lack of available information about self directed support and personalisation. Training and the provision of better information are required.

People are keen to look at local solutions with ideas such as the use of cottage hospitals, local care homes as well as further development of care at home. Training and staff development across the services was identified as a need particularly training around end of life care. Overcoming the challenges around resources is about recognising the skills everyone brings. We need a shared approach from all parties with all services working

together and with the person, carers, people's wider networks and the public to co-produce individual responses to meet people's needs and to develop new ways of providing care and support in the local community.

The Way Forward

Keep asking people what they want

We need to see a huge shift from service centred care to person centred care; where a person has choice and control and is treated with dignity and respect.

More events of this nature would help people to start talking about this sensitive subject and reduce stigma

Perhaps the word 'patient' should be consigned to history along with 'lunatic' and 'retarded'. It might help attitudinal shifts and training if patients retained their identity as people when they enter the medical system. Certain issues came up over and over again:

- Making wishes known about end of life care – advance directives - and advance care planning
- Difficulty in accessing services – public and hospital transport; plus the increasing cost of car travel
- Somewhere to stay for family members when coming from the far east and west of the region
- The need for advocates and supporters
- Continuity of care with interagency working
- Training
- And last but by no means least – information about not only what services are available but also how to gain access to them and how they work.

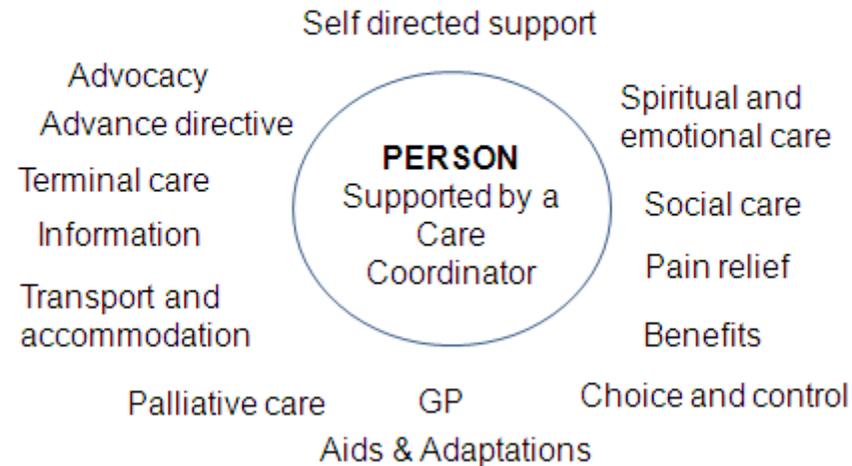
This information was compiled from facilitator feedback. There were many more comments from participants, too many to include in this report, but the main issues have been recognised and will be highlighted through the future of the stakeholder working group. Some comments from the days have been included in the bubble quotes. The only differences that emerged between the Dumfries and Stranraer feedback was that transport and accommodation issues were voiced as main concerns from the Stranraer event. Otherwise the same issues were highlighted at each event.

Conclusion

What came out of the two very full days was:

- Concern about end of life care with no signposting or information
- There is no clear pathway. It feels chaotic and uncertain
- Person centred care is the way forward
- Writing advance directives, like wills, should be seen as a normal everyday thing that everyone does.

PERSON CENTRED CARE



We are establishing a working group of representatives of all agencies concerned. We need to bring together research and work already done which will significantly inform the group. The aim will be to draw up a comprehensive strategy for end of life care.

Alongside the work of the group consideration must be given to the immediate implementation of these initiatives:

- The writing of advance directives
- A 'fit for purpose' aids and adaptations service
- Keep the general public informed as the strategy develops

With the integration of Adult Health and Social Care between NHS Dumfries and Galloway and Dumfries and Galloway Council and the new build infirmary expected to open in five or six years' time, this is a golden opportunity to review ways of working and put in place new strategies fit for 21st century social and medical care at the end of life.

Indeed, end of life matters do matter. We need to do our best to get it right. There are no second chances for 'a good death'.

Thank you

DGVoice extends grateful thanks to everyone who made these events a success and a good starting point to devise an End of Life Strategy:

To the Scottish Health Council who have provided both funding and administrative support

To NHS Dumfries and Galloway and Dumfries and Galloway Council for funding

To all the facilitators for their hard work over two very full days

To Jeff Ace, Chief Executive NHS Dumfries and Galloway and Hazel Borland, Director of Nursing, NHS Dumfries and Galloway who opened the events

To Professor David Clark, Director of Interdisciplinary Studies, Glasgow University and Amy Wright, DGVoice Director, our speakers

To John Glover who acted as timekeeper for the discussions. His strict time keeping contributed in no small part to the success of the events

To the Princess Royal Trust for Carers and the Newton Stewart Cancer Drop-In Centre who staffed the quiet room and volunteers who provided assistance at the events

To everyone who attended and contributed to the discussions, without whose input we would have no starting point to begin to build a strategy



Thank you indeed for such a well organised and pleasant conference.



This is one of the best events I have attended. Information from display tables, participants and facilitators has been excellent. All facilitators good and have not imposed their ideas on the group.

Facilitators at the events:

Sue Benyon, Welfare Benefits Coordinator, Dumfries and Galloway Citizens Advice Service

Claudine Brindle, Princess Royal Trust for Carers

Fidelma Eggo, Social Work Services, Dumfries and Galloway Council

Morag Halliday, Age Scotland

Jenny Henderson, Alzheimer Scotland

Valerie Heppel, Cruse Bereavement Care Scotland

Alex Little, NHS Dumfries and Galloway

Dr Lindsay Martin, NHS Dumfries and Galloway

Murdo Macleod, Building Healthy Communities, NHS Dumfries and Galloway

Kate McIntyre, NHS Dumfries and Galloway

Philip Myers, NHS Dumfries and Galloway

Eileen Partridge, Dumfries and Galloway Citizens Advice Service

Anne Sweetin, DG Direct and Care Call

Andy Todman, Care and Repair in Dumfries and Galloway

Alan Whiteside, DG Direct and Care Call

Dr Ann Wilson, DGVoice

Dr Libby Wilson, Friends at the End

Information stands at the events:

Age Scotland

Alzheimer Scotland

Building Healthy Communities

Cruse Bereavement Care Scotland

Dumfries and Galloway Citizens Advice Bureau

DG Direct and Care Call

DGVoice

Friends at the End

Inclusion Scotland

Care and Repair Dumfries and Galloway

Princess Royal Trust for Carers

Scottish Health Council