Approved minute

Cross-Party Group in the Scottish Parliament on Palliative Care

Convener	Vice-Conveners	Secretary
Michael McMahon MSP	Jamie McGrigor MSP Dennis Robertson MSP	Mark Hazelwood

Unapproved minute of the meeting of the Cross-Party Group in the Scottish Parliament on Palliative Care

Wednesday 21 March 2012 at 5.45 pm
Committee Room 4, Scottish Parliament Headquarters

Present:	Dennis Robertson MSP (Vice-convener)	Member for Aberdeenshire West
	Siobhan McMahon MSP	Member for Central Scotland
	Richard Simpson MSP	Member for Mid Scotland and Fife
	Billy Andrew	Strathcarron Hospice
	Sandra Campbell	NHS Forth Valley
	Rev Stuart Coates	Association of Palliative Care Chaplains
	Shirley Fife	NHS Lothian
	Dr Belinda Hacking	NHS Lothian
	Arlene Honeyman	CHAS
	Dr Sandra McConnell	Ardgowan Hospice
	Dorothy McElroy	Ardgowan Hospice
	Maria McGill	CHAS
	Annamarie McGregor	Royal Pharmaceutical Society
	Dr Alistair McKeown	Prince and Princess of Wales Hospice
	Bruce Nicol	Marie Curie Cancer Care
	Euan Paterson	RCGP (Scotland)
	Fiona Reid	NHS Highland
	Anne Robb	NHS Tayside
	Geoff Sage	St Andrew's Hospice, Airdrie
	Ros Scott	CHAS
In attendance:	Pauline Britton	Scottish Partnership for Palliative Care
	Dr Pat Carragher	CHAS
	Mark Hazelwood	Scottish Partnership for Palliative Care
	Dr Dermot Murphy	NHS Greater Glasgow and Clyde
Apologies:	Jamie McGrigor MSP	Member for Highlands and Islands
	Michael McMahon MSP	Member for Uddingston and Bellshill
	Phil Atkinson	
	Alison Blezard	Scottish Kidney Federation
	Derek Blues	Scottish Partnership for Palliative Care
	Dr Duncan Brown	St Columba's Hospice
	Dr Cameron Fergus	NHS Borders
	Peter Hastie	Macmillan Cancer Support
	Dr Peter Kiehlmann	NHS Grampian
	Elaine MacLean	Care Inspectorate
	Dr Hazel McCutcheon	NHS Lothian
	Irene McKie	Strathcarron Hospice
	Dr Gordon McLaren	NHS Fife
	Clare Murphy	St Margaret of Scotland Hospice

Apologies (cont.)	Professor Scott Murray	University of Edinburgh
	Dr David Oxenham	NHS Lothian
	Jayne Scotland	NHS Lothian
	Helen Simpson	ACCORD Hospice
	Elizabeth Thomas	St Margaret of Scotland Hospice
	Maggie White	Marie Curie Cancer Care

Action

1. Welcome, introductions & apologies:

Vice-Convener Dennis Roberson MSP chaired the meeting in the absence of Chairman, Michael McMahon MSP who was currently on compassionate leave following the recent death of his mother. On behalf of members, Mr Roberson offered condolences to the McMahon family.

Mr Roberson welcomed everyone to the meeting. A special welcome was given to guest speakers Dr Dermot Murphy (Consultant Paediatric Oncologist at the Royal Hospital for Sick Children, Yorkhill) and Dr Pat Carragher (Medical Director at the Children's Hospices Association Scotland (CHAS)).

Other MSPs attending that night were Siobhan McMahon, Member for Central Scotland and Richard Simpson, Member for Mid Scotland and Fife.

Introductions were made and apologies were noted as on previous page and above.

2. Minute of previous meeting of Wednesday 16 November 2011

The minute of the meeting of Wednesday 16 November 2011 was adopted as a true and accurate record of proceedings.

Proposed by: Maria McGill Seconded by: Dr Pat Carragher

3. Matters arising from the previous meeting of 16 November 2011

3.1 ***Good Life, Good Death, Good Grief*** (agenda item 4)
Mark Hazelwood (Director of the Scottish Partnership for Palliative Care) reported that the official launch of the *GLGDGG* had taken place on 22 November 2011 with over 70 invited guests in attendance representing a variety of organisations.

Media coverage of the launch was very positive with articles in both the Herald and the Scotsman as well as STV featuring the launch on its 6.30 pm news bulletin that evening. Further details of the media coverage could be found on the *GLGDGG* website: www.goodlifedeathgrief.org.uk

The film *'Twenty Takes on Death and Dying'* commissioned by the Partnership and made by Rosetta Life was available to view on the website at http://www.goodlifedeathgrief.org.uk/content/20_takes/

There were over 200 Alliance members to date, including seven NHS Boards and the Scottish Government's Joint Improvement Team. Facebook and Twitter accounts had also been created for *GLGDGG*.

4. Discussion: *Paediatric Palliative Care in Scotland: How did we get here and where are we going?*

Dr Dermot Murphy and Dr Pat Carragher delivered the presentation which opened with a timeline of key developments for paediatric palliative care in Scotland since 1982, the year Helen House opened as the world's first children's hospice. Rachel House (Kinross) opened in 1996 and in 2005 Robin House (Balloch) was opened.

A few definitions were given, including those of palliate, life-threatening, life-limiting and ACT's (Association for Children's Palliative Care) definition of children's palliative care (2009).

It was a rare thing for a child or young person to die but such an event impacted greatly on others. The diagnosis of a life-limiting condition for a child or young person was extremely important, as it meant that children and families then had time to become accustomed to and live with the likelihood that their child would not live beyond adulthood, allowing time for anticipatory grief before the family's impending loss. Children and young people were now almost fully aware of their diagnosis and able to participate in discussions around their treatment and care should they so wish.

1999 data from the Registrar General for Scotland around all cause mortality in Scotland for under 15's and figures around the main causes of child mortality: by sex and age, from 1998-2000 in England & Wales were given and comparisons noted.

Death certificate data for children and young people was useful but only told a partial story eg a child might die of acute appendicitis but other current life-limiting conditions would not be noted. Doctors were likely to underestimate the number of children with no diagnosis or those who lived unexpectedly into adulthood, and a Leeds University study (March 2012) in conjunction with Martin House Children's Hospice in Yorkshire, and the Children's Hospital, Cardiff confirmed that there was a likely underestimate of numbers. Death certificate data was vital and needed to be modernised. Source data too for epidemiology needed to be improved.

Determining which children and young people had palliative care needs had been examined by *Living and Dying Well's SLWG(6),* chaired by Dr Pat Carragher, by considering Professor Scott Murray's surprise question:

> *"Would you be surprised if your patient was deceased within one year?*
> *If not, they probably have palliative care needs."*

For children and young people, this had been modified to:

> *"Would you be surprised if your patient was deceased within 5 years?*
> *If not, they probably have palliative care needs."*

Link to the recommendations for service configuration for adolescents and young adults with palliative and end of life care needs produced by SLWG(6):

http://www.scotland.gov.uk/Resource/Doc/924/0105556.pdf

In the normal order of things, a child did not die before his/ her parents. Paediatric palliative care was different from that of an adult because families had to live with the possibility that their child would die before reaching adulthood because there was no curative therapy. The importance of the quality of life for that child and the rest of the family should be considered carefully, keeping a careful balance between beneficial and harmful effects of the child's treatment. Every family was different in their pursuit of treatment, but parents who understood cost benefit analysis were much more conservative in decisions around their child's treatment.

Palliative care was not separate from other aspects of holistic care in that aspects of palliative care that were equally relevant regardless of prognosis included symptom management, psychosocial care and quality of life (which differed from child to child). Aspects of cure-oriented treatment that was relevant to palliative care included death on active treatment and chemotherapy with small chance of cure.

Staffing levels for general and specialist children's palliative care services in Scotland were discussed and it transpired that by definition there was currently not a fully trained palliative care paediatric physician in Scotland.

The Scottish Children & Young People's Palliative Care Executive Group (SCYPPEx) was formed in December 2010 on the request of the Scottish Government's *Living and Dying Well* initiative to give a unified response to the requirements for palliative care for children and young people in Scotland as a whole. SCYPPEx had been involved in developing/ taking forward the NHSScotland Resuscitation Planning Policy for Children and Young People (under 16) including the Children and Young Persons Acute Deterioration Management (CYPADM):

http://www.scotland.gov.uk/Resource/Doc/924/0109739.pdf

The CYPADM looked similar to the adult version but had more measures in the form of 6 tick-boxes (the senior consultant could tick more than one box) appropriate for a child, ranging from full resuscitation to no resuscitation. Measure 5, comfort and support to the child and family, was causing a lot of discussion.

Whilst it was mandatory for a senior paediatric consultant to sign off the CYPADM form, there was an option for the form to be co-signed by the patient, parent or witness. Some parents wanted to be actively involved in decisions whilst others were content to agree with the consultant's recommendations. The policy provided guidance and clarification for parents regarding the process of making and communicating resuscitation planning and decisions. Involvement of the young people themselves was quite fluid: where a young person wanted to be involved in the decision, he/she would be consulted and their views recognised.

The Cancer Plan for Children and Young People in Scotland was due to be published soon as was the Framework for Palliative Care for Children and Young People in Scotland.

The outcomes suggested in the framework included that:

Health boards should:

1. appoint a lead doctor and nurse for children's and young people's palliative care
2. know their own incidence and prevalence of children and young people with palliative care needs in their own area

and all children and young people with palliative needs should:

3. have equitable access to palliative care which is flexible, planned and patient-centred, and takes account of their physical, emotional and spiritual needs
4. have good symptom management which will enable them to be cared for and die in their or their families' preferred place
5. be provided with safe and effective care delivered efficiently and on time by appropriately trained staff using a GIRFEC approach (Getting it Right for Every Child). This was the national programme which aimed at changing the way adults thought about how they could help children and young people reach their full potential.

http://www.scotland.gov.uk/Topics/People/Young-People/gettingitright

Transition had become more of an issue in recent years, since there were now a group of young people living into adulthood with what had once been considered *children's conditions*. The age at which people were *transitioned* to adult services varied considerably, and might be from any age between 14 and 19 depending on the setting.

Children's Hospice Association Scotland (CHAS) had 2 hospices in Scotland, provided an expanding home care service (new one in Aberdeen) and was working with adult hospices, to look at improving care for those aged between 18 and 25 years old. CHAS was currently looking at the upper age range for young people but this had not yet been agreed.

CHAS was also working to identify external organisations throughout Scotland with whom to explore the possibility of partnerships which would give a better opportunity to meet the needs of young people who could then access services best suited to them.

Current services provided by CHAS included short planned breaks, community group sessions, pain/symptom management, emergency care, CHAS at Home, 24-hour advice for families and professionals, bereavement care and support, social work support, volunteer peer befrienders, partnerships with other organisations and raising awareness.

In transitioning young people from children's to adult services, families also needed to be supported through this transition, as they were the ones who provided 24-hour care. The life experiences of young people who had grown up with a life-limiting condition were quite different to those of young people who had developed life-limiting conditions in adulthood.

Numbers were not huge - there were only 296 children and young people currently using CHAS services – however this was a 20% increase from January 2011. Of these, there would be between 45-60 deaths per year. Over the past couple of years, the number of children dying who were under one year old was increasing whilst the number of young adults dying was decreasing. In 2008 there were 55/140 deaths (0-19 years) within 28 days of birth.

Partnerships throughout Scotland would give a better opportunity to meet the needs of young people who could access services best suited to them. The partnership working approach was chosen because it delivered choice, offered individually tailored care options, delivered services closer to home, offered complementary skills and expertise and involved new and innovative projects.

The dying trajectory of young people was often that of sudden death.

http://www.chas.org.uk/

Following the presentation, a discussion ensued the main points of which being:

- the four Nurse Consultants posts for Children and Young People's Palliative Care funded by Diana monies were not continuing in that guise after March 2012 - there would be some sort of service provision in their stead but a decision at government level had still to be reached
- *Together for Short Lives* was the new name for ACT and Children's Hospices UK
- on referral to CHAS not all families chose the hospice option – some opted for the home care service, called CHAS at Home which offered care to families in their own homes when they needed it most
- the launch of the CHAS at Home Aberdeen service took place in November 2011 – this was comprised of two nurses and a support worker who would work closely with Paediatric Consultants in Aberdeen
- experiences so far of the partnership working approach adopted by CHAS had demonstrated both opportunities and challenges
- CHAS was keen to work with statutory services to progress primary, secondary and tertiary care in order to augment and improve its services through joint-working
- future service development and training should address deprivation through cross-sector working
- there was a void in some respects around the provision of services for children and young people but there were also some areas of excellence eg around diabetes or cystic fibrosis
- the young person should be at the centre and in control of his/ her own healthcare but some professionals were still providing paternalistic services and making decisions for the patient without realising it, thus affecting the young person's autonomy
- it was vital to maximise the young person's empowerment around his/ her own transition to adult services whilst he/ she had a good quality of life
- the Scottish Youth Parliament (SYP) was the democratically elected voice of Scotland's young people and was committed to ensuring young people were heard by the decision makers of Scotland - the SYP had a number of subject committees including one for Health and Wellbeing the Convener of which was Andrew Deans.

Age related health issues and problems were discussed there.

On behalf of the group the Convener thanked Dr Murphy and Dr Carragher for their delivery of the presentation and members for participating in the discussion. The presentation can be downloaded from the Partnership's website at:

http://www.palliativecarescotland.org.uk/

6. Any other competent business:

On this occasion there was no other competent business.

7. Date of future meetings:

- 20 June 2012 (+AGM), Committee Room 6
- 12 September 2012, Committee Room 4
- 12 December 2012, Committee Room 4

On behalf of members of the Cross Party Group, Mark Hazelwood thanked Mr Robertson for chairing that night's meeting.

There being no further business the meeting closed at 7.15 pm.