

## **Cross Party Group on Cancer in the Scottish Parliament**

**Meeting, Wednesday 12 June 2013, 5.30pm**

Present:

Malcolm Chisholm MSP, Co-convener [Chair]  
Jackie Baillie MSP  
Vicky Crichton, Cancer Research UK  
Lynne Barty, Brain Tumour Action  
Hamish Guthrie, carer  
Shanne MacNamara, Edinburgh Centre for Neuro-oncology  
Craig Harrison, The Brain Tumour Charity  
Gus Ironside, The Brain Tumour Charity  
Peter Hastie, Macmillan Cancer Support  
Heather Rankine, Boehringer Ingelheim  
Sheena Dryden, NHS Lothian  
Janice McClure, Brain Tumour Action  
Rob Lester, Edinburgh and Lothians Prostate Cancer Support Group  
Ian Hay, Edinburgh and Lothians Prostate Cancer Support Group  
Dawn Crosby, Teenage Cancer Trust  
Alistair Haw, Prostate Cancer UK  
Ellen Finlayson, CLIC Sargent  
Jan Anderson, Neurological Alliance  
Kerry Napuk, Edinburgh and Lothians Prostate Cancer Support Group  
Sandra Campbell, NHS Forth Valley  
Evelyn Paterson, NHS Forth Valley  
John Wyke, Scottish Cancer Foundation  
Alice MacGregor, Brain Tumour Action  
Jim McGugan, Brain Tumour Action  
Lorraine Dallas, Roy Castle Lung Cancer Foundation  
Lesley Harrison, The Brain Tumour Charity  
Carol Cochrane, Brainstrust  
Rachel McAndrew, Paediatric Oncology Research Nurse  
Joannie McCutcheon, Scottish Neuro-oncology network  
Stella MacPherson, SCAN patient rep  
Roseann Haig, Circle of Comfort  
Joan Love, Brain Tumour Action  
Hilary Campbell, Breast Cancer Care  
Leslie Horne, Edinburgh and Lothians Prostate Cancer Support Group  
John Laydon, patient  
Prof James Garden, University of Edinburgh  
Roy Rampling, SANON  
Daphne Chad, RHSC

Apologies:

Nanette Milne MSP, Co-convener  
Alison McInnes MSP  
Helen Eadie MSP  
Stuart McMillan MSP  
Mike Shaw, Edinburgh and Lothians Prostate Cancer Support Group

Prof Alan Rodger  
Bill Paton, Napp  
Dr Colin Selby, NHS Fife  
Shirley Fife, NHS Lothian  
Sara Taylor, Almirall  
Peter Phillips, SCAN patient rep  
Julie Uttridge, ISD  
Prof. Bob Steele, Scottish Cancer Foundation  
Mhairi Simpson, RCN  
John MacGill, GSK  
Bruce Nicol, Marie Curie Cancer Care  
Karen Bell, Cancer Research UK  
John Sleith, REHIS  
Dr Alex Holme, NHS Lothian  
Karen McNee, James Whale Fund  
Suzanne Spencer, Cancer Research UK Ambassador

## **Agenda**

Malcolm Chisholm welcomed attendees to the meeting.

### **1 Minutes of last meeting**

The minutes were approved as a true record of the meeting.

### **2 Listen to the Fallout: Support Needs for Brain Tumour Patients and Carers**

Malcolm Chisholm introduced the speakers. Lynne Barty of Brain Tumour Action opened by explaining that there is little recognition that there are over 120 types of primary brain tumour, and this leads to a wide variation in patient experiences. Brain cancer is rare and often not well understood, even within the clinical community. Specialised interventions are needed at various points and patients often have very complex needs, which places a huge burden on carers. This is often accompanied by feelings of fear, guilt and isolation. The charities and support groups which exist are small, and don't receive any central funding. She called on the Parliament to support their work.

Gus Ironside outlined the recent merger of The Brain Tumour Charity through with the Brain Tumour UK. He welcomed the opportunity for patients and carers to share their story in Parliament. Patients often have complex needs which the NHS, social services and charities find challenging to meet. Mr Ironside noted that better support is needed in the community.

Hamish Guthrie then told the story of his experience of his son's brain tumour and the impact it has had on the family. When his son was diagnosed, aged 2, they were told the probability of his surviving the necessary operation was around 50%, with a life expectancy of 3-5 years. He is now 30 years old, and has had multiple health problems since, although it's not clear if all of them are related to the brain tumour.

He attends multiple clinics and the impact on his carers is considerable. He has many medical issues as well as personal support needs. While he has a funded weekly care package, he needs 24 hour care, which his parents provide.

Mr Guthrie noted that while some aspects of his care have been well co-ordinated, others have not. Services seem unable to take a holistic approach to his needs and the NHS hasn't assessed the impact on his carers. There is little long term planning of care or respite for carers.

Craig Harrison explained that he was working in the US when he was rushed to hospital with a seizure, and later diagnosed with a life limiting, inoperable brain tumour. He is married and has two children. He had multiple treatments, and physiotherapy to help him to regain some strength in his arm and leg. He is still living with the effects and has had to give up work, which he really loved and has lost his financial security. He also explained the massive impact it has had on his family. He is now on Employment Support Allowance, but noted that he is unable to receive the sort of concessions available to those on Job Seekers Allowance and he had had to negotiate with DWP on motability issues, which he found very hard to deal with when he was unwell and undergoing treatment.

Mr Harrison praised the work of charities in raising awareness, investing in research and providing support to patients and their families. He stated that both he and his wife had found the support groups very helpful. He stated that he felt guilt about the impact on his wife and children, for what they're dealing with now, and for what the future may hold.

Shanne MacNamara explained that the different types of brain tumour, and their location in the brain, means they can affect people in many different ways. Symptoms are often non-specific and can be very hard to diagnose. There are also many different pathways and outcomes. Some patients may have a very poor prognosis, with others living for many years with a tumour. There are often multiple health care professionals involved in a patient's care, so liaison is very important. Part of the role of the specialist nurse is to provide co-ordination and a single point of contact. They provide advice and information to patients and carers, but also to primary health care professionals and hospices, as the rarity of the condition means many are unfamiliar with it.

Ms MacNamara noted that diagnosis is frightening and difficult and a positive outlook can help. Support groups provide a vital service, but the rarity of the disease means that innovative approaches are needed in rural and less populated areas.

Malcolm Chisholm thanked all of the speakers for their very powerful contributions and opened the discussion to the floor.

The group discussed the challenge of multiple health care professionals being involved and the fact that this often leads to people having to constantly explain their medical history to new people. The lack of continuity is a major factor. It was noted that CNSs have a key role to play in providing this, but not all areas have them. MDTs are also important.

It was also agreed that more needs to be done to improve patient involvement. The Scottish Adult Neuro-oncology Network does have a degree of patient representation on it, and The Brain Tumour Charity has a patient and carer involvement group. It was noted, however, that this is often challenging because of mobility and communications problems. A new project – Neurological Voices – is being developed for patients to give feedback to the NHS on their experiences and is looking for volunteers.

There is a major challenge that as the health service specialises, there is a great need for holistic approaches, particularly in complex diseases like this. There was also a discussion about the fact that people often feel lost when they finish active treatment, so the link between acute, primary and social services is vital. The group considered whether a case worker would be helpful, or whether the GP might play this role. Many of the patients present agreed that they had felt very lost when they left hospital, but still felt they needed support. It was noted that the Transforming Care After Treatment programme would seek to address these issues and to pilot solutions, but it would be a long process.

Malcolm Chisholm thanked all those who had participated in the debate.

### **3 Scotland Against Cancer Conference**

It was noted that a provisional booking has been made for Monday 18<sup>th</sup> November at Surgeons' Hall in Edinburgh. Further details will follow. Suggestions for topics and speakers should be sent to Vicky Crichton.

### **4 AOB**

Vicky Crichton informed the group of a free public talk entitled 'Genetics: the new fortune telling?' that Professor Nick Hastie is giving at the Botanic Gardens on 27<sup>th</sup> June in celebration of the Medical Research Council's Centenary Year.

Roseann Haig informed the group of a presentation on the Circle of Comfort and NHS Fife pilot project on 17<sup>th</sup> June at the Carnegie Library, Dunfermline.

### **5 Date of next meeting**

The next meeting of the group will be Wednesday 11<sup>th</sup> September at 5:30pm. The topic is still to be agreed. The agenda will be circulated to members once it is confirmed.