

Cross Party Group on Carers

Committee Room 3, Scottish Parliament

12 March 2014

Note of meeting

MSPs: Claudia Beamish, Joan McAlpine

Individuals and organisations: Alun Ellis, Scottish Government; Aisha MacGregor, Scottish Government; Bruce Nicol, Marie Curie Cancer Care; Cath Logan, Big Lottery Fund; Dylan Hamilton, PASDA; Elspeth Molony, The Stroke Association; Ian McCourt, Falkirk and Clackmannanshire Carers Centre; John McFarlane, Renfrewshire Carers Centre; John Spence, Falkirk and Clackmannanshire Carers Centre; Jude Clarke, Division of Clinical Psychology, BPS; Kirsteen Shaw, Marie Curie Cancer Care; Lesley Jeffrey, Dumfries and Galloway Carers' Centre; Linda Whitmore, Enable Scotland; Rebecca Marek, Scottish Youth Parliament; Richard Meade, Marie Curie Cancer Care; Sebastian Fischer, VOCAL; Sue Northrop, Carers Scotland; Susan Swan, Marie Curie Cancer Care.

Claudia Beamish welcomed everyone to the meeting. This meeting of the CPG was the Annual General Meeting. No formal nominations for office-bearers were received, and Claudia Beamish and Joan McAlpine were proposed to continue as co-conveners by Jude Clarke and seconded by Sebastian Fischer. It was agreed that Carers Trust Scotland should continue as secretariat to the group, with Heather Noller currently fulfilling this role. The idea of a subscription for organisational group members was discussed, as it was noted that some CPGs do this and are able to provide food at lunch meetings. Jude Clarke stated that although a nominal subscription of between £10 and £20 may suit some people, many organisations were members of several CPGs and costs could easily mount up. It was decided that the group membership (as detailed on the group's web page and annual return) would participate in an electronic vote on subscriptions, with this vote to be administered as soon as possible by the secretariat.

The minutes of the previous meeting were accepted with two minor clarifications, moved by Rebecca Marek and seconded by Jude Clarke.

Claudia Beamish spoke about how positive the last meeting of the group was, and advised that she had to leave this meeting at 2pm but was looking forward to hearing about the discussion later.

Speakers from Marie Curie Cancer Care gave a presentation about their Confident Caring pilot project. Nurse Specialist Susan Swan spoke about the pilot (slides are available) and future plans for the project. Claudia thanked Susan and the Marie Curie staff for presenting to the group and said how inspiring it was to hear that the programme had had such a great response from carers, but also how worrying it is that so many people providing end of life care do not understand enough about the illness the person has.

Jude Clarke spoke about her project developing a signposting website¹ and work on a feasibility study to support mental health carers. She noted that the carers who took part in the Marie Curie programme had been found via a carers' centre and wondered how hidden carers were located. Sue Northrop praised the use of local networks and mentioned dementia-friendly towns in East Lothian which were being developed along the same person-centred lines as the programme – listening to what people want. Sebastian Fischer stated that this kind of programme was really important and should be rolled out across Scotland. He also spoke of a similar programme from the University of Edinburgh and wondered if the Marie Curie programme was linked in with this. Sebastian also noted that the programme seemed to focus on physical/practical support as opposed to emotional support, and also wondered about the inclusion of post-caring support as there is a lack of recognition of former carers. Lesley Jeffrey stated that the Dumfries and Galloway Carers' Centre has recently changed its remit to support former carers for up to 24 months after the end of their caring role, and that this had been very well received.

Kirsteen Shaw from Marie Curie said that they were conscious of the need for emotional support as part of the programme, and that one to one support was offered to the participants if it was required. Local information was also provided so that participants could seek support themselves. Susan Swan added that the assessment tool developed as part of the programme would be delivered to all the participants of the next pilot for use in their own individual assessments, and that specific needs could be addressed in 1 to 1 time. Nurse specialists were seen as having the right skills to deliver emotional support and this was therefore a key part of the programme. Kirsteen said that in many cases it was easier for the carer to speak about their need for emotional support in a group of other carers, rather than in front of the person they look after.

Claudia Beamish asked if the Cross Party Group could take forward any findings or issues raised from the pilot programme. John McFarlane expressed the view that hopefully the ethos of the project could be taken within the NHS, as many people's experience of the NHS is not good and there could be lots of learning from this project. Sue Northrop and Jude Clarke asked if the assessment tool could be circulated, and Bruce Nicol said that this would be possible. Rebecca Marek asked if any adaptation had been considered to make the programme more suitable for young carers; this was being considered by the steering group to be looked at in the future. Funding for continuing the programme was discussed, with particular reference to providing increased emotional support. There was some discussion about the value of nurse specialists in delivering the programme - a clinical background was helpful when delivering the programme, which volunteers would probably not have, but carers may be able to provide emotional support to their peers as part of the programme. It was pointed out that nurse specialists were able to educate carers as well as support, particularly in the difficult period following a terminal diagnosis when carers need to be supported quickly. Both speakers from Marie Curie stressed how much they had learned from carers over the course of the programme and had been able to implement this into their work, e.g. knowing that carers in crisis do not always process information efficiently so some things may have to be revisited.

Claudia thanked the contributors from Marie Curie and suggested that this topic should be revisited when the programme has progressed further. John McFarlane suggested that in order to support the programme, it may be useful to collate the different types of support that are available within the

¹ <http://healthwholeofme.com/>

voluntary sector and write to NHS boards to highlight this. Elspeth Molony stated that a mapping exercise would be more useful if it looked at all support for carers rather than just palliative care. It was noted that the CPG may not have the capacity to carry out a mapping exercise. It was agreed that the University of Edinburgh report would be circulated to the group.

Proposals for Carer Legislation: consultation

The discussion moved on to the proposals in the Scottish Government's consultation for carer legislation. Proposals for a Carer Support Plan (to replace Carers' Assessments) were discussed; Sebastian Fischer said that a duty was preferable as a power could lead to inequity, but there will be a battle to secure this. A duty would mean that people in intensive caring situations could be supported much earlier in the caring journey. Lesley Jeffries said that figures from Dumfries and Galloway Council revealed that out of 14,000 carers in the area, only 222 had received a carers' assessment, and queried what difference would actually be made to the lives of carers. Jude Clarke agreed that carers must be empowered to approach the Council for an assessment.

Sue Northrop thought that the proposals were not transformative and were a missed opportunity to support carers, and that the whole set of proposals needed to go further, changing the culture of caring. John McFarlane said that it all began with identifying carers, and spoke about a programme in Renfrewshire's GP surgeries that helped identify carers. He also spoke about concerns regarding situations where the carer lives in a different local authority to the person they are looking after, and whether the costs of deciding who pays for what would begin to mount up and reduce the amount of money that is available to carers. Elspeth Molony stated that information and advice for carers must be timely, appropriate and accessible to people who do not have internet access or who have literacy issues. Linda Whitmore reiterated the need for accessible information for carers that would help to empower them – many people with a learning disability also have caring responsibilities and it is important for them to access information in a format that is suitable. Sue Northrop felt that information provided to carers must be made available in spaces that carers are already accessing - GP practices, pharmacies, churches, schools and other community venues. Information should also be more person-centred.

Joan McAlpine asked if anyone wanted to make any points about carer involvement. Rebecca Marek said that young carers do like short breaks but would prefer more flexibility, recognising that a break from caring does not have to mean going away somewhere but could be more creative. Joan said she was aware of this sort of break happening in Dumfries and Galloway, and Lesley Jeffrey confirmed that breaks in the area were focused more on carer outcomes, giving the example of someone who had been supported to grow vegetables in a greenhouse because this was identified as being able to meet their outcomes. Lesley also spoke about her experiences being a carer as well as working for a carer support organisation – she is invited to lots of groups and meetings, and sometimes feels underappreciated. Carers need to see the value in being involved, and also make sure that they do not lose out financially when they participate. Jude Clarke agreed, but said that it could be done without affecting carers' benefits. Jude asked the Marie Curie staff whether they had paid carers' expenses when attending the pilot programme. Sue Northrop agreed with the previous points made, saying that it is easy to get paid staff around a table but it can be difficult to get action; carers don't have performance indicators and the meetings they are invited to are not 'work' for

them. It was also pointed out that hidden carers were, by their nature, excluded from these groups and meetings.

Joan McAlpine acknowledged that identifying carers was a big issue, and touched on the points in the proposed legislation about increased identification of carers through GP registers. Sebastian Fischer spoke about the hard fight to get GPs to hold registers of carers and working this into the GP contract, but cautioned that merely registering carers would mean nothing unless something further, such as a referral, would happen. He pointed out that Scotland has a very good infrastructure to support carers, and this must be built on by enabling better identification of carers. Joan said that she was aware of people who did not know about carer support (and other) services in their area, and wondered how aware GPs were of what they could refer to. It was pointed out that some GPs were more knowledgeable than others, and reiterated that there must be something more than a register to make sure that identified carers were actually supported. Jude Clarke asked that whatever is brought in by the legislation should not discourage grassroots work, speaking about her own website that was developed due to an identified need because the information required was not held by NHS Inform or similar sites. She also stated that people should not be disadvantaged if their own GP did not have a carers' register or sufficient information to refer to support, and so national resources such as websites could go towards plugging this gap. A number of people reiterated the need for GP practices to share good practice, such as GPs in Tayside providing regular health checks for those identified as carers. John McFarlane said that the enthusiasm of the voluntary sector in supporting carers needs to translate to other sectors, going above and beyond the minimum level of support.

Sebastian Fischer reiterated the requirement for the duty to support carers to pass into legislation, as this is the most important way to secure rights for carers. It was noted that CoSLA have stated that they don't believe new legislation for carers is necessary. Jude Clarke stated that evaluation needed to be part of any new legislation, making sure that the impact was measureable and that all communities were included and covered. Linda Whitmore spoke about the need for emergency planning to be included in the legislation, referring to her experience of working with older parents caring for adult children, who worry a great deal about emergency care planning.

AOCB: Rebecca Marek told the group about a consultation event that is planned for young carers on Saturday 12 April in Edinburgh, and asked for details to be circulated.

The next meeting of the Cross Party Group on Carers will be held on Tuesday 6 May 2014, at 5pm in the Scottish Parliament. The topic and further details will follow.