

The Coalition of Carers in Scotland

Minutes 27th May 2009

Present:

Mary Stewart	Fife Carers Centre
Bill Middleton	Fife Carers Centre
Seb Fischer	Voice of Carers Across Lothian (VOCAL)
Claire Cairns	The Coalition of Carers in Scotland
Alan Scougal	The Coalition of Carers in Scotland, Gairloch Community
Rosemary Nicholson	GAMH
Tricia Morrison	Argyll and Bute Carers Network
Diana Buchanan	GSWCC
Tony Fitzpatrick	North Lanarkshire Carers Together
D MacGillivray	Carers of West Lothian
Joyce Moore	West Glasgow Carers
CMcGinty	Castlemilk Carers
Margaret Lynch	Carers North Glasgow
Jane O'Donnell	Carer, North Glasgow
Thomasina Shar	Carers S E Glasgow
Jean Chapple	Carers S E Glasgow
Ellen Moffat	Carers S E Glasgow
A McLuckre	Carers S E Glasgow
Helena Kelman	Lanarkshire PRT Carers Centre
Eileen Churchill	Glasgow South East Carers Centre
Rosemary Kennedy	South East Carers Centre
M Donnelly	
Diane Goodman	Renfrewshire Carers Centre
Cath MacGilchrist	Fife Carers Centre
Christine Hoy	Scottish Government
Teague McFadden	Glasgow Social Work
Donna Mulder	Carers Centre Falkirk
Agnes McMillan	Carers Centre Clackmannanshire
Jacqueline McBeath	Moving on Project
Josephine McGill	Glasgow S E Carers Centre
Rosemary Kennedy	Glasgow S E Carers Centre
Mary-Denise McKernon	Carers of West Lothian
Rhona Stewart	Independent Advocacy, Perth and Kinross
R Stokes	GAMH
Teresa Martin	Glasgow Social Work Department
Dave Clark	GEECC
Liz Hay	North West Carers Centre
Fred Beckett	North Carers GCC
Richard	Carers Liaison and Support Project
Sam Clarke	North Lanarkshire Carers Together
Lesley Fishleigh	Lanarkshire Carers Centre
Wendy Laird	VOCAL
MMcIntyre	East Renfrewshire Carers
Sheena Munro	Highland Community Care Forum
D Scullion	Glasgow NE Carers
Iain Love	Glasgow S E Carers
June Whale	PRT Dundee Carers Centre
Ann Hamilton	CAST
Diane Brines	Alloa Carers Office
Moira Oliphant	Scottish Government
Suzanne Aitken	Glasgow N E Carers

Maureen McClure	Glasgow Parents, S.W Carers
James Duncanson	GEECC
Kevin Geddes	LTCAS
Ross Grieve	Thistle Foundation

1. Welcome and Announcements

Alan welcomed everyone to the meeting and emphasised the important relationship between long term conditions and unpaid carers. He hoped this meeting would help to forge links and build relationships between organisations working on behalf of people with long term conditions and their carers.

Alan then made the following announcements:

- The Coalition has received a reply from Shona Robison in relation to questions raised at the last Coalition meeting which Bill Kidd promised to bring to her attention. Copies are available on request.
- Copies of 'Guan Yersel' The Self Management Strategy for Scotland produced by the Long Term Conditions Alliance are available. Kevin Geddes will be providing details of this in his presentation
- Everyone should have received an Information Pack on arrival. This includes details of several consultation events, members may be interested in participating in, these are:
 - The Scottish Government is launching its action plan for mental health improvement 'Towards a Mentally Flourishing Scotland' This will take place on the 11th June at Dynamic Earth in Edinburgh
 - Carers Scotland and the Social Work Inspection Agency will be holding a conference at the Radisson Hotel, Glasgow on Tuesday, 1 September 2009. SWIA, together with Carers Scotland will be presenting their findings from inspections and identifying key themes and best practice.
 - The General Medical Council is consulting on new draft guidance, *End of life treatment and care: Good practice in decision-making*. The guidance is intended mainly for doctors, but may also help patients and the public, and other health and social care staff, to understand what they can expect from doctors involved in caring for patients with a terminal illness. The consultation runs until 13 July 2009.
 - The British Medical Association are consulting on General Practice and have produced a document called 'General Practice, the Way Ahead' This includes proposals for improving access to services and providing out of hours services. This consultation is open until the 12th of June.
 - The next meeting of the Coalition will be held on the 26th August and will be in the Concert Hall in Perth

2. Christine Hoy, Long Term Conditions Unit, The Scottish Government

Christine outlined the government's strategy for long term conditions

3. Kevin Geddes, The Long Term Conditions Alliance (LTCAS)

Kevin outlined the work of the Long Term Conditions Alliance, including:

- The Self Management Strategy for Long Term Conditions in Scotland
- The Self Management Fund for Scotland. This is a £2 million fund which will be distributed over the next two years to projects furthering the self-management agenda.
- The Hub - A resource in the centre of Glasgow providing computer access, desk facilities and meeting rooms

After his presentation. Kevin took questions from the floor.

Q: How can organisations access a grant from the self management fund?

A: All the information and application forms are on the LTCAS Website. Any community group can apply, it doesn't have to be a charity.

Q: In your strategy you emphasise self-management and don't acknowledge the role of carers in this. In some cases carers are at the heart of managing long term conditions. This needs to be reflected more.

A: Hopefully people can influence this in the future. There is a carer, Wendy Laird, and representative from the Coalition, Claire Cairns now on the LTCAS Board. Certainly It is difficult to find the balance with self-management.

4. 'Looking to the Future' Donald's Story

This short digital story produced by the Scottish Government's Joint Improvement Team illustrated how receiving the right support can help people manage their condition and improve their quality of life.

5. Ross Grieve, Thistle Foundation, Self Management Training

Ross illustrated how people with a long term condition can be assisted to self manage their condition through training. This training can also assist carers in managing their caring role.

6. Question, Answer and Discussion Session

Q: Has the Thistle Foundation ever run its self management training with people with mental illness or their carers? and are they able to provide this training through local organisations?

A, Ross Grieve: Yes, both a specific course and our generic course have been provided to people with a mental illness. Some people attended independently, others had support needs. Regarding running the training with other organisations. The Thistle Foundation has applied for a grant to the Self Management Fund to enable it to provide training to organisations so that they can run the training themselves.

Comment from carer: I have been involved in a STEPS programme which has allowed me to take control of my situation. I was referred through my G.P

Q: In theory this training sounds brilliant. I care for 3 people and have a heart condition. I can't get the support to attend. Could you go to the carer, rather than them coming to you?

A, Ross Grieve: It is possible. We would be keen to look into this.

Q: It is great what we have heard today. What is being done to change the attitudes of social work and health staff. We need to change the culture and see patients and carers as experts. This needs to be embedded in practice.

A, Christine Hoy: Things aren't joined up, due to different funding streams. We will have someone on each board looking at joining up the different services. It is important to have this in local authorities and health

Comment:: We need to take a leap of faith to support carers and patients. People are still chasing their own targets

Q: People should take charge of their own conditions, but it is important that people recognise carers are also part of this process, including sometimes the cared for person

A, Ross Grieve: There can be challenges in relationships between carers and the people they care for. We need to recognise there are needs on both sides. Some of the techniques on the self-management programme may help to address this.

Comment: When setting out enhanced services for G.Ps there should be a requirement for supporting carers, to establish a carer register and provide signposting etc

A, Christine Hoy: I would support this. I worked in a practice where this happened and it should be the same across the board. It should be part of incentives

7. Sebastian Fischer, VOCAL Carers Centre

Seb put forward the case for increased rights for carers, by outlining:

- The case for moving from 'Recognition to Rights'
- What rights carers currently have in law
- The need to include carers rights in Scotland's new Carers Strategy
- What rights carers should have

8. Question, Answer and Discussion Session

Q: The question of carer benefits is a Westminster issue. Is there a role for Scottish government

to push this with Westminster, or should they be asking for more power?

A: There is an upcoming debate in the Scottish parliament on carers. I will be informing our MSP of the issues and this will be raised as an issue.

Q: My son's school has been on strike several times. As carers can't go on strike, we just have to get on with it. This is emotional blackmail

A: Strikes are not an option for the majority of carers. Militant action is not right for the carers movement. The Carer Poverty Protest March was an example of how we can raise issues and win rights in other ways.

Comment: I was always told that with rights come responsibilities. Well, carers have all the responsibilities, but no rights.

9. Discussion Groups

Participants were asked to discuss the following:

- What do you think of the idea of working towards a set of Carers Rights?
- What rights should be included in Scotland's Carers Strategy?
- Which of these rights are the most important to you

A feedback report is available and has been submitted to the Government's Carers Strategy Working Group.

10. Final Remarks and Closing

Alan thanked all the speakers and everyone for coming.

A copy of all presentations are available by contacting Claire Cairns at Tel: 01786 825529 or E-mail: coalition@carersnet.org