

Cross Party Group on Carers

Committee Room 4

13/06/13

Note of Meeting

In attendance:

MSPs:

Claudia Beamish (co-convener)
Joan McAlpine (co-convener)
Graeme Dey
Jackie Baillie
Sarah Boyack
Michael McMahon

Individuals/organisations:

Moira Oliphant, Carers Policy Unit, Scottish Government
Simon Hodgson, Carers Scotland
Peter Hastie, Macmillan
Lisa Ross, Mindroom
Clare Lally, Carer
Michael Grieve, Carer
Derek Steele, Carer
Tom White, PASDA (Parents of Autistic Spectrum Disorder Adults)
John McFarlane, Renfrewshire Carers Centre
Kathleen Taylor, Renfrewshire Carers Centre
Maureen McClelland, PAMIS (profound and multiple learning disabilities)
Michelle Stewart
Alison Stevenson, Shared Care Scotland
Lorraine Allen, Carer
Lewis Thomson, Carer
Tarynn Cornell, Scottish Parliament

Claudia Beamish welcomed everyone to the meeting and introduced herself. It was decided that in order to ensure all attending MSPs were able to hear the carers' stories, the official business and election of the co-convener would be postponed until after the carers had spoken.

Clare Lally spoke about her caring role; she had prepared to be a parent, not a carer. Her daughter Katie has multiple disabilities, which means that Clare has to be a doctor, physiotherapist, nurse and carer, as well as being a mum. She pointed out that providing care is easy, but the fighting for recognition is hard. **Michael Grieve** spoke about caring for his wife, which he has done for eight years. His wife suffers from chronic pain. He was not prepared for the daily struggle and fight for recognition, for financial help, or for the effect on his relationship with family.

Michael McMahon thanked both Clare and Michael for speaking, and mentioned that his wife was a carer for their daughter, and always felt they struggled to get support, getting dismissed when they were trying very hard. When their daughter accessed her medical records, it had been noted that her mother was seen as 'pushy'. **Michael Grieve** and **Tom White** both noted that they had been called aggressive and bullying when speaking with health care professionals about the people they care for. **Lorraine Allen** pointed out that if the person being looked after is not able to interact with health or care professionals, the professionals can think they know best – but they must give people greater opportunities to say what they want. This includes carers. **Tom White** agreed that sometimes people cannot articulate what they want or need and this can cause problems.

Jackie Baillie noted that some people had been caring for a long period of time but didn't seem to have seen any changes. She asked what needed to be further addressed to make things easier for carers. **Sarah Boyack** agreed that she was keen to hear further discussion on what needed to change.

Joan McAlpine introduced herself as a new member of the group. She has a caring situation in her close family and has been able to see the issues and support available first-hand.

Jackie Baillie proposed **Joan McAlpine** as co-convenor of the group. This proposal was seconded by **Graeme Dey**.

Claudia invited the group attendees to introduce themselves and spoke briefly about Carers Week and the theme 'Prepared to Care?' She invited participants to discuss this theme.

Tom White noted that caring can be short-term or long term, and one of the greatest fears for carers is the possibility of taking on a long-term caring role and worry about what will happen if they cannot continue to provide care. Secure structures for care and support need to be put into place in order to alleviate this worry for carers. **Lorraine Allen** pointed out that some people do not like being looked after by local authority social care services and this can cause problems in contingency planning. **Tom White** said that he was happy with what was being provided now, but worried about the future. **Lorraine Allen** noted that care workers tended to be on very low rates of pay and this was a cause for concern, as it led to high staff turnover and no consistency of care. **Tom White** felt that care work is not seen as a vocation and this is something that needed to change at a school level.

Claudia Beamish asked if there were any suggestions about how to prepare for longer term care. **Maureen McClellan** said that PAMIS had had a conference about planning ahead and the evaluations had asked for specific support for young carers, and also for transition to adult services. **Claudia Beamish** asked if information and learning from this conference could be shared, and acknowledged that care workers' pay was a pressing issue. **Tom White** pointed out that some paid care workers receive only 5p per hour more than the minimum wage and this is not possible to live on. **Jackie Baillie** agreed that payment for carers and for paid care workers needs to be higher and care must be valued more highly. It was seen as imperative that the commissioning and procurement process that local authorities undertake should not drive costs down – quality must come first. Commissioning must be

creative. The Public Bodies (Joint Working) Bill and the forthcoming Procurement Reform Bill are both opportunities to influence this.

Graeme Dey spoke about local authorities and how they can be seen to be tokenistic when it comes to support for carers, particularly young carers. He spoke about a specific incident in his own constituency where there was a policy for young carers but the social work department wasn't aware of this. He had to step in to ensure that changes were made and the policy became fit for purpose and widely used. **Michelle Stewart** said that as a councillor from West Dunbartonshire Council, she was aware that good policies were sometimes not followed through and this led to people being let down. This is very wrong and it is important to make sure policies do not go lax.

John McFarlane noted that funding was an issue – if funding is only for one year or three-year periods it is extremely difficult to follow policies through if the funding does not allow for staff or projects to stay in place. It was also noted that policies and documents from the Scottish Government were not written in accessible language and it's difficult for ordinary people to feel involved and consulted if the documents are not written in everyday language.

Claudia Beamish pointed out that she had approached local authorities about their support for young carers through schools, and wondered if there was an opportunity to push this further and see exactly what policies and strategies are in place. She noted that schools' applications of local authority policies could also vary. The annual Scottish Young Carers Festival, due to take place on 2-4 August 2013, will provide an opportunity to consult with young people on how their school supports them as a young carer.

Lewis Thomson spoke about his caring role; he has been a carer since the age of 10 and had very little support. He had to leave education because of the lack of financial support, as students are not eligible for Carer's Allowance. He had attended some support groups for a while but had wanted actual tangible help in the form of regular breaks from caring – short one-off breaks were of little use because the caring situation would still be there on his return. **Lorraine Allen** also noted that she had to leave full time education because of her caring role and the financial issues this had caused for her because she was unable to receive Carer's Allowance. She pointed out that the support she had received from her own local authority had been good and wondered why this good practice could not be repeated in other local authorities. It was noted that Carer's Allowance is set by the UK Government but there are opportunities for the group and the Scottish Parliament to make recommendations. **Claudia Beamish** assured the group that many of the points they had made required ongoing discussion and further meetings of the group could look at the issues in detail. She asked what other future agenda items group members would like to discuss.

Kathleen Taylor noted that mental health did not always get the support and services it required, perhaps due to stigma. The available services are not always right for people. Graeme Dey said that transition from children to adult services continued to be an issue as there was often no specific handover. **Jackie Baillie** asked if the group had considered the self-directed support regulations consultation that was currently going on. It was agreed

that the points made about Carers Allowance were something that the group could make a public statement on after further discussion. **Simon Hodgson** pointed out that when the Carers UK Caring and Family Finances enquiry was completed later in the year, there would be a report and up-to-date information. It was agreed that a meeting in September would be useful to discuss the SDS regulations and also the finances enquiry.

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Graeme Dey asked if CPG meeting times could be more suitable. It was agreed that this would happen.

Next meeting: Wednesday 25th September, 12:30pm, TG20.21, Scottish Parliament. Agenda to be confirmed.

Action points:

- **Carers' Allowance and carer finances** – this was seen as a key issue that the CPG may want to make recommendations on. Carers UK are currently conducting an enquiry into carers' finances and will be producing a report in 2013 – there will be a Scottish report produced by Carers Scotland. **A CPG should be convened when the report is published in autumn 2013 in order to discuss the findings and next steps.** The National Carer Organisations submitted evidence to the Expert Group on Welfare Reform in March 2013, drawing attention to carers' financial and welfare reform issues. This evidence was noted in the response to the report that was published in June 2013. The NCO outlined a welfare reform model that would be more appropriate for carers and disabled people, which may be of interest to the group.
- **Mental health** – it was agreed that mental health carers were an often overlooked group and that a CPG looking at issues faced by mental health carers would be useful. **A meeting in autumn 2013 could consider mental health carers.**
- **Self-directed support regulations consultation** – the group has not formally considered the SDS regulations and guidance that is currently out for consultation. However, the National Carer Organisations have produced a briefing on the key points of the consultation that will be circulated to the group. The response to the consultation from the National Carer Organisations can also be circulated for comment if required. **It was agreed that the SDS regulations should be on the agenda of a meeting in autumn 2013.**
- Carers of young people who are transitioning from children to adult services – this was raised by the conveners in autumn 2012 as an agenda item for the November 2012 meeting of the CPG. However, none of the invited carers were able to attend the meeting due to unforeseen circumstances. **This topic can be raised again at future meetings of the CPG.**

Appendix: presentations from Clare Lally and Michael Grieve

My name is Clare Lally and I am here tonight with my partner Derek and friend Michelle. I am full time mum/carer to my twin daughters Holly and Katie, the Twincresses. The girls are now 6 and a half and were born 12 weeks premature, as a result of the birth Katie suffered brain damage and was left unable to walk, talk and swallow – she is fed via a button in her tummy and she is also a silent aspirator which means she can choke and you can't hear it so we have to watch her 24hours a day to prevent this! She is such a clever girl she can also use this to manipulate a situation as well. Holly our other daughter has no health issues, she is a beautiful girl with patience of a saint however I do feel I let her down a lot. So the theme of this week's Carer's Week is prepared to care? Was I prepared ...to care? No I wasn't, I was preparing to be a mum for the first time.

I wasn't prepared for the continuous bad news we were getting for Katie, every day/week there was always something else wrong.

I wasn't prepared to bring my children into the world and then spend every day thinking is this the last day we have with her.

I wasn't prepared to have to learn all the various pieces of medical equipment we have to use on a daily basis.

I wasn't prepared to feel I was letting down my other daughter because so much time focuses on Katie who isn't well.

I wasn't prepared for friends and close family to Abandon us at a time we needed them the most!

I wasn't prepared for other Carers to be so horrible and nasty because I was campaigning and speaking out!

I wasn't prepared to have to constantly fight and battle with services for services!

These are just some of the things I was not prepared for! But, now these are the things I am not prepared to let other Carers go through – we have to be prepared for things and we can do this by preparing together. If we had been told before we came home from hospital with the girls all the things we would have to go through, all the fights and battles we would have to deal with I really don't know if we could have done it! There is no amount of preparation could prepare you for what lies ahead. For me the 24hour care of Katie is the easiest part of life, the hardest part is all the fights and challenges! I was on Call Kaye phone in the other morning on BBC Good Morning Scotland, and one of the things I said was we need a huge needle and thread to start sewing up all the loopholes and nets we all fall through! Well, we are that needle and thread, we can start sewing them up because we know what they are because we are the ones who have fell through them! We have to make changes not just for us but for the Carers who will be coming behind us so they do not have to go through the same hurdles and challenges that we have all had to.

And on that note I will thank you for listening and giving me the time to speak

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Good Evening, my name is Michael Grieve and I am going to speak to you about being Prepared to care.

I have been a carer for my wife Claire for about 8 years. It is quite hard to say when I really started being a carer, as my wife's illness has deteriorated over time. She suffers from Chronic Pain but it was eight years ago I gave up work as a Programmer Analyst with the Edinburgh Woollen Mill to become a full-time carer. The Chronic Pain she suffers from has become more debilitating and now her loss of mobility has reached the stage that she currently is stuck in her bed 24/7 so she is only out of bed to go to the toilet. At the moment this is a real struggle for her to achieve but she struggles and fights every day to do things that you and I take for granted.

- I was not prepared for the financial implications of me being a full-time carer having been used to a reasonable income from working full-time.
- I was not prepared for having to fight for my wife to get the Benefits that she is entitled to.
- I was not prepared for having to see my wife in pain and not be able to do anything about it.
- I was not prepared for being called a bully when I stand up for the person I care for.
- I was not prepared for the heartache our Children would go through when they see their Mother in Pain.
- I was not prepared for the lack of support from friends and family. My Family don't live near enough to give physical support but the emotional support they give helps immensely.
- I was not prepared for having to fight every step of the way.
- I was not prepared for how it would affect our relationship however that has not been a negative thing we are closer now than we have ever been. We laugh we joke we get through the day.

I was not prepared for the fact that I would experience that which few fathers have and be at home and help and guide my children's growth I am proud of all three of my children they are all doing the most with their education Our youngest Daughter is just starting 5th Year and our Eldest Daughter is in 6th Year. However it is our son who has gone to Abertay University and is a Student Nurse. His time spent with his mum after leaving school and before going to University had an impact on him which is why he chose nursing.

I have campaigned for or against one thing or another all my life and it was I suppose inevitable that I would become a campaigner for carers. The profile of Unpaid Carers has been increased over the past couple of years but it still has a long way to go a lot of people and yes politicians among them still don't get the work that the Millions of unpaid carers do every day.

There are still people out there who don't identify themselves as carers we have to reach them and get them over the stigma that being called a carer means that you are an "unpaid skivvy" as one person described how they felt about the term to me.

I would like to see Carers getting the respect and recognition they deserve not hidden away as a cheap solution to the cuts in health and social care.

Without organizations like the local carers centers, The Princess Royal Trust for Carers and Carers Scotland I don't know where the campaign for carers would be. I am privileged to do work with all these organizations and I have not met a group of People more committed to fight for the organizations they represent.

Organizations like the Royal College of GPs are now developing policies on carers and ensuring a greater understanding of the role of carers among GPs.

The Co-op Retail stores have adopted The Carers Trust as their charity of the year and hope to raise £5 Million, I am proud to be one of Scotland's Carers Ambassadors and as such go to stores and help them understand what carers do and provide a local contact for events and support.

However the fight continues there are new carers every day and I will continue to fight for them not to go through what I and many others have. Clare Lally and I have developed an online presence in the form of a Blog and are both shocked and pleased at the great response it has received. Posts may be in fits and burst but we hope to have "Guest Bloggers" to speak of their experiences.

My whole outlook on life has changed since becoming a carer I believe for the better when you have to spend your time thinking of someone else and putting their needs before your own it makes you realize that some of the small things in life don't really matter.

I believe that yes there are negative impacts on your life at the moment when you become a carer but the benefits you can get can far out weight them.

Thanks for listening.

