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INTRODUCTION

Welcome to the report of the fifth Carers Parliament which was held at Edinburgh Conference Centre, Heriot Watt University in Edinburgh on 2nd November 2016. We hope you find this of interest.

The event was chaired by journalist Ruth Wishart and organised by Carers Scotland on behalf of the National Carer Organisations and commissioned by the Scottish Government.

This report is broken down into the following three sections:

- **REPORT OF MORNING SESSIONS**
- **CONSULTATION ZONE WORKSHOPS**
- **REPORT OF AFTERNOON SESSIONS**
Introduction

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MINISTERIAL FOREWORD

by AILEEN CAMPBELL MSP, Minister for Public Health and Sport

“ I am delighted to present the report of the fifth Carers Parliament which was held at Heriot Watt University in Edinburgh on 2 November 2016.

Since the first Carers Parliament in 2012, Scottish Ministers have taken the opportunity to hear the voices of carers from across the country, and to listen first hand to many personal examples of the challenges which carers face every day. I would like to thank each and every one of you for participating in the discussions, debates, and for sharing your experiences over the past five years.

The fifth Carers Parliament, yet again, provided good conversation and debate. Jeane Freeman MSP, Minister for Social Security, and I were delighted to meet with many of you – from our constituencies, from across Scotland, and with our international guests.

In a video message to delegates, Nicola Sturgeon MSP, First Minister of Scotland set out our vision for a Scottish Social Security system based on dignity and respect, our plans for implementing the Carers (Scotland) Act, and the progress being made with initiatives, such as Carer Positive, that are making a real difference to adult and young carers.

As many of you will be aware, the Carers Act takes effect next April. Together with carers, our National Carer Organisations, local authorities, health boards, COSLA, and other key partners, we have been working hard to ensure the provisions in the Act are successfully implemented.

There has also been real progress on ensuring that changes to Carer’s Allowance, and the new package of support for young carers, have a positive impact on the lives of carers.

The decision not to hold a Carers Parliament in 2017 was taken to focus attention on these crucial policies and the legislation.

Instead we have been able to hear the views of carers across a number of consultations, experience panels, working groups, and meetings. Again, the dedication and enthusiasm of carers in helping to inform new policies and legislation has been extraordinary.

The Carers Parliament will be reconvened in 2018, and I have asked the seven National Carer Organisations to begin planning and organising, as well as considering alternative ways to engage with all carers as we move forward. I look forward to hearing more about this, and to attend next year’s event.

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Minister for Public Health and Sport
REPORT OF MORNING SESSIONS
Good Morning ladies and gentlemen, my name’s Ruth Wishart and it’s my very great pleasure and a real privilege to be chairing this, the 5th Carers Parliament today.

It’s a very important opportunity for Scotland’s army of carers to meet, to network, to have an opportunity to question the policy makers and of course to share some of their own experiences.

I think you’ll all agree we’ve been on a number of journeys since the Parliament first came into being and as you know the Carers Scotland Bill was passed in February of this year and will be implemented hopefully next Spring.

There are representatives of the Scottish Government here today in the afternoon and we will hear a keynote address from Aileen Campbell, MSP, the Minister for Public Health and Sport.

We also have a number of distinguished guests with us here this morning including the Assistant Chief Minister for Jersey, Senator Paul Routier and International representation from Finland, Portugal, Germany and Ireland.

Your fame has spread far and wide. Now you’ll appreciate that our First Minister has had just one or two things on her mind since a second vote on June 23rd, but she has always supported this event and because of that she has recorded an address especially for this morning so please welcome our virtual First Minister, Nicola Sturgeon...
Good Morning everybody and a very warm welcome to the fifth Carers Parliament. I’m delighted that you are all attending this event and that we welcome so many delegates from around the world.

I’m really sorry that I’m not able to join you today but I’m delighted that Aileen Campbell, Public Health Minister and Jeane Freeman, Social Security Minister are attending because I know from my own experience of last year’s Carers Parliament at Murrayfield what a fantastic event this is.

It’s a chance for all of you, the people who have the real life knowledge and experience of caring, to discuss and debate the issues that matter most and it’s a vital chance for us to hear directly from the people who really understand the support that carers need.

Last year I spoke about the Carers Bill now the Carers Act which we were then steering through Parliament and I announced that we were making amendments to the Bill to reflect what we had heard from carers in forums and consultations up and down the country.
You told us that the issue of emergency planning was important so there are now provisions in the Carers Act that ensure this issue is discussed as part of the new Adult Care and Support Plan and Young Carers Statement.

This is just one example where your wealth of knowledge and experience has made a real difference to the way that we improve support for carers and ahead of that legislation coming into force in April 2018 we will work with all of you and with National Carer Organisations, Integration Authorities, Local Authorities, Health Boards and other key interest to ensure that it’s provisions are delivered.

We also want to hear your views on some of the other key measures we are taking to support carers. We pledge to use the new powers of the Scottish Parliament to establish a Social Security System based on dignity and respect.

That includes Carers Allowance which we will raise to the same level of Job Seekers Allowance. We are continuing to support the integration of Health and Social Care to deliver primary and social care in local communities. We will consider a national or regional approach to supporting carers and cared for people.

We are also considering how best to increase the use of the Carer Positive Scheme so that more of Scotland’s employers sign up to offer flexible practices and support for carers in employment. I know that Aileen and Jeane will speak in more detail about these efforts and our vision for a healthier and a fairer Scotland. But today is really all about you.

Please take this opportunity to engage and share your views. By doing so you will be making a real difference to the services and the decisions that affect you as carers on a daily basis. I look forward to hearing about the discussions and the outcomes of today and I wish you all the best for a successful and constructive event.

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INTRODUCTION TO THE ADDRESSES

by RUTH WISHART, journalist

Ruth Wishart

Ladies and Gentlemen as the years have gone past, Carers Scotland has gained an appreciation of what your concerns and priorities are for this day and they have devised a schedule accordingly so there’s a line in your pack which says “Ruth Wishart for the day”. The photographer just suggested it sounded a bit like “thought for the day”, I promise you it’s not!

We are going to be hearing shortly, as you’ve heard, from Jeane Freeman MSP, the new Minister for Social Security which is surely a pivotal role given the upcoming changes now in the benefit system which is partially devolved and will be putting some of your most urgent questions to her afterwards.

Similarly, Peter Johnston the Health and Wellbeing Spokesman for the Convention of Scottish Local Authorities will be sharing his thoughts with you and will also be taking questions afterwards. Then we are going to have the first of two powerful interviews with a carer, both of which illustrate the different ways they face challenges in their everyday lives because of caring.

That brings us to our facilitated discussions on a whole range of issues covering all the new legislation in areas of employment, education and mental health. This is a pretty vital part of the day where you can all swap notes and share your experiences and concerns.

I know that you have signed up for these facilitated workshops and in a perfect world we would all be sitting at the same table as these are taking place but as it’s not a perfect world could you use the lunch break to check which of these tables you should be at. It’s colour coded and so indeed are you. You needn’t worry ladies and gentlemen about missing out on what’s happening in other groups because before, during and after lunch there will be ample time to look at other people’s ideas from making communities more carer friendly and for shaping best practice in our services.

Graeme Reekie will be here at 12:15 to give you more details about how and where this will all be made available and at 1:00pm you will be very glad to hear there will be lunch.

Now you may know ladies and gentlemen that all Scottish MSPs are required to register any outside interests or gifts so in the interest of transparency I suppose I should record that she visited a distillery in the course of her constituency work she was given two miniatures of gin!

Please welcome Jeane Freeman...
Thank you very much, thank you Ruth.
I have to say they were very wee miniatures so I was delighted to receive them, just a wee bit disappointed at their size.

Can I start by thanking you all very much for this opportunity to be with you this morning.

It’s great to see so many carers from across Scotland and indeed joined by our friends internationally who have made the effort and taken the time to be here and a particular welcome to those who are here from my own constituency.

I want to talk a little bit as Ruth said about the new Social Security powers that we will have devolved to the Scottish Government. Those powers cover 15% of the total UK spend on benefits and the system that we will design will be a first for Scotland.

You know when our Scottish Parliament reconvened we took over the Government of the day at that time, took over the responsibility for existing Scotland specific institutions. We took over Health, Education, Justice that
already existed and had a legal framework and successive governments have worked in their own ways to try and adapt and improve those but Social Security is something we’ve never had responsibility for so we are designing and building this with you from scratch. The scale of it is significant and the complexity of it is too.

We have 15% but that 15% has to work alongside the 85% of responsibility for the rest of the benefit system that will continue to be the responsibility of the UK Government and the DWP. We need to be able to design a Social Security System for Scotland that can work in tandem with that DWP system. Our starting point as a Government is threefold. First of all it is to say very clearly that in our view Social Security is an investment that we all collectively need in ourselves and in each other and none of us know the day that might come when we will need to look at that Social Security system for the help and support that we need. So it is time to change the culture and the toxic rhetoric that exists around benefits and I’m saying that ours will be a Social Security system. Some of the principles that I’m going to outline, I hope that we are already beginning to make those changes and we continue to do so over time.

The second thing we’ve said that I think is important is that we will work from the premise that everyone who comes to the door, if you like, of the Social Security system in Scotland does so because they need to. Nobody chooses to be disabled, nobody chooses to have long term poor health, and nobody indeed really chooses to be a carer. You do it because you love those that you care for and you believe that it’s the right thing to do. We will not be treating people on the basis that everyone who comes to us is somehow ‘at it’ and trying to get more from the system than they are entitled to and they deserve. It’s my firm belief that the current UK system works from that principle and consequently makes people jump through a significant number of hoops in order to prove any entitlement that self-evidently they have.

The third important characteristic will be those principles that the First Minister touched on. The Social Security system in Scotland will be founded on the principles of dignity, fairness and respect. Our job will be to make those principles come alive in everything that that system does, how it treats people and how it does its business and indeed how it treats those who work for it.

We know for carers 47% live in the most deprived areas caring for 35 hours or more a week but twice as many live in those deprived areas than do in the more advantageous areas. We also know that there is a gender question here; that woman are four times more likely to give up employment in order to take on caring responsibilities than men are. This is also what we do in Social Security and how we work with carers to design the Scottish Carers Allowance. It’s also about tackling inequalities in the design, the shape and the operation of that new Social Security system for Scotland.

We've just finished a three month consultation which I know that many of you have contributed to. In that three months we held over 120 events, we reached over 3,000 people directly engaging in the consultation and so far we have received over 400 responses. We deliberately set out the consultation to give an indicator of how we intend to build the new system for Scotland and that is by directly engaging with three groups of people.

The first of those are those with direct experience, lived experience of the benefits that we will take responsibility for, you being one such group. The second are those with particular experience in providing advice and support who have expertise in the whole area of the UK benefits system, who understand how one benefit relates to another because what we can’t
We've also said though that we will look and the First Minister made a particular commitment in terms of young carers, not only to look at whether or not some level of financial award would make a difference but also to look at the overall package that's available for young carers in terms of educational opportunities, understanding of the role inside education and elsewhere so that their lives can be made a little bit easier and we are currently working with their organisations to try and devise what the best package could be.

So what happens next? As I said, the intention in the consultation was to give a pointer to how we are going to work over the next four and a half years to design, build and deliver on that 15% of benefit responsibility. To do that the best way is to continue to engage with those three groups of people so we will launch a recruitment exercise for 2,000 volunteers to join our experienced panels. Those will be people from the groups that currently are in receipt of the benefits that we will take responsibility for. So people receiving Carers Allowance, people receiving Disability Living Allowance or now transferred over onto Personal Independence Payment, people with experience of funeral poverty, people with experience of receiving cold weather or winter fuel payments and people with experience of receiving the sure start maternity grant which we are improving on and changing to the best start grant.

Those experience panels are there to work directly with me – and with officials in Scottish Government – to help us make sure that, as we devise the policy changes and the system that we want to implement them, that
we double check that what we think is a good idea actually corresponds with what people expected when they gave us their views during the consultation. In addition, we’ll begin two other key work streams, one with those individuals with direct experience of delivering welfare advice and support and one with those who have a significant degree of expertise and understanding the whole benefit system so that we can make sure that the inter dependencies are thought through between what we do in Scotland and what happens in the UK. So that we don’t get to a point where we hit unintended consequences and that we understand the consequences of our decisions before we take them.

The third group will be people with direct experience or an expertise in delivering a payment system. The overall objective in all of this has to be the safe and secure transfer of benefits.

The one group of people who cannot suffer because we’ve not gone about this in the right way, we’ve been too hasty or too slow, we’ve not thought through properly everything that we need to do, the one group who cannot suffer because of that are those in receipt of the benefits that we are being responsible for. We should get to a point where people receive the money they are entitled to on the day that they are entitled to it at the level they expect and frankly they neither know nor care which Government click the send button that sent the money to their account. So we need to take our time to get this right, that doesn’t mean that we won’t do anything for the next four and a half years. It does mean that where we can take over responsibility for smaller scale benefits affecting smaller numbers of people, we will do that. We will make policy decisions and announcements so that people know what to expect, we will review the landscape across Scotland of advice and support services to make sure that it is comprehensive no matter where you live, so there will be gaps and there will be duplication in the current landscape and we need to fix that so that individuals will get the information in the clearest terms that they need to understand what benefits they might be entitled to and how to go about it and they will then be pointed to where they will get advice and support to help them navigate that system and that information will cover all the benefits where they are devolved to Scotland or not so that people know everything that they are entitled to.

The central thrust in all of this is to shift how we think about Social Security in Scotland, how it’s portrayed and how we talk about it – and make it important that we all understand it is an investment in ourselves and each other. And, wherever language is toxic, unfair and dismissive, it is changed. Where the processes that belittle individuals and make them feel as if they are asking for something that they are not entitled to are ended and we do all of that only by working together with your expertise, your lived experience, your knowledge to help make sure that we get it right. It is complex, it’s big, it’s challenging but it is also an absolute opportunity for each and every one of us.

For the first time to design a public service in Scotland for Scotland, I am certain that with your involvement we will get it right and I very much look forward to continuing to work with you in order to make sure we do that.

I am certain that with your involvement we will get it right and I very much look forward to continuing to work with you in order to make sure we do that.
Ruth Wishart
Thank you very much Minister, you'll not be surprised to learn that we've got a huge number of questions relating to your new role.
You'll know through your trade union days that the easiest way to try and cover a lot of ground. So all of these questions came from people involved in caring but some, many of them overlapped of necessity. If you'll bear with me I hope to cover as much ground as possible in the next little while.
The first question Minister is:

Q
I am currently studying a full time degree, this equates to 21/2 days in class and ten hours on placement. That means I'm still caring for more than 35 hours a week yet I can't claim Carers Allowance.
Now when a carer is trying to improve the future for their family, why should they be penalised in this way?

Jeane Freeman
Yes, I'm not surprised by the question and you won't be surprised either that in the course of the last three months or so, in fact longer than that, I've heard this from a number of carers and I agree absolutely.
The key thing that we need to try and do is support people in their caring responsibly both financially and in other ways as best we can. But also look at the eligibility criteria and the earnings cap and look to change those so that people can continue to have a life alongside caring and can plan for their life after caring.
I've heard from folks who are in their 40s or their 50s who gave up their job to care for elderly parents, the elderly parents perhaps then move into full time residential care, or indeed die and the individual is now at a cliff edge where their Carers Allowance stops and they've had no opportunity because of the restrictive criteria around the existing system to themselves pursue education, additional skills training, in other words to look ahead to their own future. So it is our intention that we will look very carefully with you at what improvements we can make in both those aspects, both the eligibility criteria that says how many hours you have to be caring before you're eligible for the allowance but also the earnings ceiling that currently applies.
RW Of course that’s not just a question for people with elderly parents, it’s a question that affects people of all stages of their life whether they’ve had to stop work, as you said, too early or whether or not they are a young person hoping to carry on their studies part time.

JF Absolutely, I attended the Young Carers Festival earlier in the summer there and a number of young carers raised precisely that point with me, as did others, particularly mothers, who had either given up their career or had not begun their career even though they might be qualified for a particular area of work because they had taken on caring responsibilities for one or more of the children and had worked very hard with others to try and get to a point where that young person could live much more independently and then having been successful in the love and support and the care they had given to secure that end were then themselves looking at this black hole about what do I do next then and what about my life.

So we need to try and find ways of looking at the criteria, looking at the earnings limit but also looking at how the other institutions in our public service, in furthering higher education and our employers understand the significant skill base and experience and organisational skills that carers would bring to either their educational studies or to the workplace as a potential employee. So there’s a lot for us to do and the Carer Positive Scheme with employers, I am keen to engage with them to help other employers understand exactly the potential that a carer brings to the workforce.

JF Yes that’s a really good question and I’m not dodging it when I say accurately the real place to ask that question is the UK Government because they set that earnings limit. And this kind of earnings limit weaves it way through all the benefit system and to my understanding, although I could be wrong, is that it is what the UK Government considers to be the maximum that people can earn while still receiving benefits and some of you may be aware that next week the benefit cap imposed by the UK Government will be reduced even further with at least a six fold impact on households affected in Scotland. So that’s their decision, their rationale, they’d have to justify to you for it.

My view and the Scottish Government’s view is that that earnings cap is unfair, it’s too low and we need to look at two things, whether or not we think there should be an earnings cap and if we do what should it be? In all of that then our commitment is to continue to engage with you to get your views about what we might do.

RW You see because people would think not unreasonably when they look at the new devolved powers that you have and devolved to your ministry what people would quite rightly assume is Carers Allowance is part of that package that you would have jurisdiction over the amount as well as over the actual benefit.

JF We do, we will have jurisdiction over the level of the Carers Allowance and what the eligibility criteria are and whether there are any restrictions in it like the earnings cap but what we have to be very careful of is the inter relationship between a benefit that we’re responsible for and a benefit that the UK is responsible for. So, for example, there is an inter relationship between pensions and other benefits and that’s what I meant earlier when I talked about not giving with the Scottish hand only to have it taken off with the other hand. So some of these decisions about how much income an individual is allowed to have while still receiving benefits continue to sit at a UK level so we might increase the level of the benefit only to find the individual’s overall income reduced by the DWP on another benefit in order to bring it down to that level. Am I making sense? Well you will know this much better than I do actually.

RW So presumably you’re going to argue with the DWP that nothing that you give, as you put it, with the Scottish hand can then be taken away with an English hand.
There is a group called the Joint Ministerial Working Group on Welfare that has on it from the UK, Damian Green who is the Secretary of State and Penny Mordaunt and Caroline Knox, the two ministers responsible and from Scotland, Angela Constance who is our Cabinet Secretary and my boss, my first boss, Nicola Sturgeon is my big boss and Keith Brown who is the Cabinet Secretary for the Economy because there will be some devolved work programmes coming to Scotland and their ministers.

The point of that group is to work through areas like that to see if we can reach agreement and if you like Ruth, you know, that’s where the arguing gets done and I hope people can rest assured that we will be doing that arguing. Both the UK Government and the Scottish Government have made an absolute commitment that whilst we understand that the two Governments are coming at this from completely different standpoints and there will be disagreements. What we can’t allow is for the Benefit System and therefore the Scottish system for Social Security to become some kind of political football that we kick about between each other in order to make political points relating to another matter. That doesn’t mean that there won’t be disagreements and arguments and we will try and find ways round and solutions. We have already had one or two of those and have found ways round which did not involve us compromising so that’s where those kind of difficulties will be worked through as best as we can. Of course, in the meantime and before I was elected indeed, groups of skilled experienced Scottish Government officials have been working over many, many months and will continue to work with DWP officials so that a lot of these issues can be sorted out at that level but where there are political differences between what the UK Government wants to achieve with its Welfare System and what we want to achieve with ours that we sort them out as best we can in that Joint Ministerial Group.

Now I imagine a paramount concern will be making that transition as smoothly as possible so there are no gap sites.

What we can’t allow is for the Benefit System and therefore the Scottish system for Social Security to become some kind of political football that we kick about between each other in order to make political points relating to another matter.

Yes it is and that is less straightforward than it might seem, I’ll give you a couple of examples. Currently the Cold Weather payment made by the DWP sits on 11 different IT systems. So 11 different IT systems have to work together in order to ensure that we get the names, addresses and relevant information of all the people in Scotland who currently qualify for that benefit so that even if we made no change we could simply take over the payment. One of the smallest benefits in terms of the numbers of people that it affects is Industrial Injuries and Severe Disablement Benefit is about just over 20,000 people.

That system at UK level is entirely paper based so I guess in a basement somewhere South of the Border there are lots of brown folders with individual cases in them and in order to get the information about the names and address, level of benefit and so on, everyone in Scotland, all 20 odd thousands of them, people will have to go into that basement, go through all those brown folders and pull out the Scottish Postcodes. Scottish officials will go in as well and double check that no Postcode’s are amiss. So just securing the data is complex and complicated before we think about what we do with it and how we design it. But securing the data and being sure that it is accurate is about 1.4m people. The 15% we
will take responsibility for will affect 1 in 4 of us, around 1.4m people, so it’s data for 1.4m human beings living in Scotland so it’s not some technical exercise, it’s about human exercise and we need to get that absolutely right in order to ensure that we do secure the safe and secure transfer of benefits. So that’s the job that needs to be done and then alongside that we need to design and build what we want the Scottish system to look like in terms of the benefits, changes that we might want to make, level of benefit, eligibility criteria and so on. The two groups of people that are largest in that transfer of benefits are people on Disability Benefits and Carers so we need to make sure that we get it absolutely right and every single person in this room today currently receiving Carers Allowance continues to receive it on the day you expect at the level you expect it to be and you don’t know, we don’t care which Government clicked the send button.

RW There’s one last question I have here Minister and it’s again against education:

Q My children’s education has been affected because of the caring role they had to provide. Why could they not have had a supplement to provide them with some private tuition which would have prevented them falling so far behind in school?

JF It is actually that kind of example and that kind of question that has prompted the First Minister to make the commitment that we would look at a Young Carers Allowance and we look at that in terms of both the potential financial component of that allowance but also having spoken with Young Carers Organisations and been at that Festival we are also looking at the overall package of support for young carers that make their lives more straightforward in terms of how understanding and knowledgeable education is about the impact of their caring responsibilities on their education and what assistance they can be given there on further and higher education, and into the workplace or into apprenticeship schemes. So the whole package, including that financial component is something that we are currently working through to see what we can do and we are doing that with young carers themselves.

RW Thank you very much. Would you join me please in thanking the Minister for Social Security, Jeane Freeman?

Ruth Wishart
Our next guest ladies and gentleman has Dundee on his birth certificate but he’s lived and worked in West Lothian for much of his adult life, it’s an area I know well since my husband was raised and born in Bathgate. Our guest is service leader of two council administrations and he is also the elected leader of the SNP at present. He’s also a non-executive director of NHS Lothian and of Health Improvement Scotland.
Please welcome Peter Johnston...
Address 2:
Peter Johnston

I'm always struck by the number of people who are here and the level of expertise and challenge that you bring. I think it's really important that we have this space and it's a safe space for us to problem solve together. Looking out into the room I can see some familiar faces who already know me as CoSLA's Health and Wellbeing spokesperson and as Ruth has already declared I have to confess to being a West Lothian councillor and also that I first got involved in local Government some thirty years ago and in recent times as Ruth has said, I have served on NHS Lothian Board but also more interestingly for me Midlothian Integration Joint Board. During that time I've seen a number of changes, changes in policy, but the one thing that

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Well thank you and I should confess that I’m no longer a director of Health Improvement Scotland.

Can I firstly thank you for the opportunity to take part in today’s Carers Parliament. This is actually the third Carers Parliament I have been invited to attend.

I’m always struck by the number of people who are here and the level of expertise and challenge that you bring. I think it’s really important that we have this space and it’s a safe space for us to problem solve together.

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has been absolutely constant is the huge contribution that unpaid carers make day in day out, year after year and thankfully our Health and Social Care system I have to acknowledge would simply collapse without that input. This only becomes truer in the current financial climate and when our ageing population means demand for Health and Social Care is growing. All this points to an urgent need to better support carers and I know that this is the reason that each of us is here today. We all want to see better support for carers. The Minister has just spoken of the difficulties from Welfare Reform due to limits on the power and the resources which we have at our disposal in Scotland. That is certainly true; she also spoke of the need to do as much as we possibly can within the power and resources we do have. Getting the financial assistance to carers is vital.

I believe it’s also important that the financial support is integrated with other tangible assistance locally to both carers and those they care for and the challenge before us all is surely to make this journey more straightforward. I, like the minister I’m sure, frequently hear from carers and those they support how difficult navigating the various parts of the system is. The challenge is to make the systems work seamlessly sharing information where consent has been given and most appropriate for the benefit of those who need it but critically also ensuring efficiency and value for money across the whole of the public sector.

Local Government, I can assure you stands ready to play a part in ensuring the transfer of Social Security is completed successfully and is there to work in partnership with everyone represented here today towards an integrated and efficient Social Security system in Scotland. Social Security is just one example of where we face challenges due to limits on resources which we have at our disposal. It’s the same for Social Care provision, we are experiencing unprecedented pressure within the Public Sector and we are using all the political levers available to us to challenge that, but the reality is that we simply have to find new ways of working to get the best from the resources that there are available. So with that in mind, what should support for carers look like? What role do Councils play in helping to make that a reality?

Many of the carers that I talk to in my own area tell me the single most important thing that Councils can do to better support carers is to get it right for the people they care for. This can be challenging, we know that if we want better quality care we have to invest in a social care workforce. Councils already pay their own social care staff the living wage or better and since this October we are now committed to using our commissioning processes to ensure that all staff providing direct social care are paid the real living wage at £8.25 an hour. We know that having to negotiate artificial barriers between different services and types of care has a negative impact on carers and the people they care for so we’re integrating Health and Social Care to deliver a more joined up service.

This will take time to fully realise but I believe we see signs already of real progress. We know that if people have more choice and control over the care and support they deliver then they achieve better outcomes so we are implementing Self Directed Support and this is generating real change in people’s experiences. I’ve emphasised that one of the most effective ways that Councils and integrated Joint Boards can support carers is by getting it right for the people you care for. We also need to focus on supporting carers to look after their own health and wellbeing, not just so you can continue caring for longer but so that you are able to have a life alongside caring. Balancing a caring role with work commitments is a huge challenge and as much Councils can do as employers for example to make a real difference CoSLA was pleased to work with the Scottish Government to develop the
Carer Positive Employer award and we hope that more and more employers will continue to sign up for this.

I recognise that Short Breaks are usually important in helping carers look after their own physical and mental wellbeing. Self-Directed Support presents a real opportunity to become more creative and how we think about breaks from caring and to develop a wider range of choices. Councils also play a major role in providing many of the services and support which are topics for your group discussions later from education and lifelong learning opportunities to employability, parenting support and I hope you’ll provide plenty of feedback and challenge on how these services can be improved.

The Carers Act will place substantial new duties on Councils. Although we remain concerned about whether it will be sufficiently funded we are committed to ensuring changes flowing from it result in better support for carers and there is much work to be done before this Act kicks in. Firstly, there is all the secondary legislation and supporting guidance that needs to be put in place but then there is also a question of creating the conditions to make sure all of this results in the changing we want to see in the months and years ahead.

I think that’s much harder and that’s where we need to make sure that we fully understand the costs of the new entitlements and that we have worked, we being CoSLA, with the Scottish Government to ensure the resources are in place to deliver these. We also need to make sure that the changes flowing from the Carers Act are properly coproduced with carers and this needs to take place both at the National and I emphasise Local level. If I can go back to the reason that I believe we are all here today, the urgent need to better support carers. For me that means consistently better outcomes for carers and those they care for. If we are going to achieve that I believe we need to leave enough flexibility in the system to allow for co-production at a local level between Councils, carers, service users, providers and local community organisations. When I say local level, I also mean the individual level. A good genuinely co-productive relationship between carers and those involved in supporting them, and those they care for is really what underpins the whole ethos of Self Directed Support and is also the best way I believe to deliver better care and stronger communities. So I really do believe that we can do this, there are undoubtedly challenging times in the Public Sector and if we can continue to work together to create safe space to problem solve together then I think we can build stronger communities that will result in better outcomes for everyone.

Thank you for listening.
Thank you very much Councillor Johnston. Again we’ve got some composite questions from the Carers Parliament delegates and they cover quite a wide range but we’ve tried to narrow them down and cover quite a few bases. The first one is:

How can Local Authorities and the NHS, and for that matter the Integrated Boards, put in place plans to truly invest into early intervention and preventative support?

For example, the question says that at the moment only those meeting high or critical eligibility criteria in Social Care are receiving support and this results in one crisis situation after another which is not very cost effective and not a good use of resources.

That’s probably a question that identifies the biggest challenge that we are facing. I touched on this on my opening remarks, the demographics are quite clear, we are facing an ageing population, the improvement service presented recently to the CoSLA Convention, information that by 2025 which is just around the corner, we are going to see a 25% increase in the 75 year olds living in Scotland and a 39% increase in those over 85 so that puts in context the demands on our Health and Social Care systems.

I recently quoted a statement by Einstein that said “if you keep doing what you always did, you’ll always get what you always got”. I think we have recognised that in Scotland and what we are looking to do is change the way we are doing things and for me the integration of Health and Social Care is fundamental to making these changes. Not just joining up services, it’s shifting the balance of care and this is where it becomes difficult.

What we’re looking and planning to do is shift a resource from the Acute Sector into the Community Sector, to shift the emphasis of spending on being reactive in the Acute Sector to early intervention prevention in the community and that is not easy.

It’s easier when resources are plenty; it’s much more difficult when resources are becoming tighter. So as part of this process, for example, CoSLA and the Scottish Government are now looking at the review of NHS targets and our health and social care indicators. We want to look to see, can we...
make these all pull together in the same direction to actually enable us to shift the resource from Acute into the Community.

A good example of that would be the target of indicator for delayed discharges and I’m sure you understand what I mean, if an elderly person or a person is deemed to be fit to leave hospital, we know that if they are in an acute bed 48 hours later their health begins to deteriorate. So that is an evidence based target with a clear outcome. If we can move that person from an acute bed into a more community setting, that delivers a better health outcome to that individual. Many of our other targets aren’t as focussed as that and they are actually pulling in different directions and stopping us from moving resources from Acute into the Community. That’s a major challenge that we are going to have to face up to. To put the resources we need to where they will be more effective and I think that’s a challenge that’s going to be a challenge for everyone in the community from politicians, carers, for everyone as we look to change things. As I said earlier if you continue to do the same things and expect a different outcome we are going to fail.

RW It strikes me listening to you that all of that can only work, that shift you’re talking about that allows us to go from preventative medicine and proactive care rather that reactive. All of that is contingent in having not just the raw facilities but the skilled personnel available in the community. At the moment that wouldn’t seem to be the case.

PJ Well I think that’s absolutely true and that’s why, for example, both Local and National Government in Scotland were committed to introducing the real living wage into added caring and because we recognised that we had to have a dedicated, high quality workforce and also to give career opportunities and these haven’t been there, you could earn more stacking a shelf in Tesco or other supermarkets as you could as an adult carer.

What that says about society is for you to judge but I think we are now recognising that we have to build up a high quality workforce to put in place the skills and the talent we need to deliver these changes. So we know what has to be done, we are working on it, it’s not going to be easy especially when we keep coming back to the financial cyclone that we are facing.

RW I just wonder if [the next question] is a supplement for that:

Q Local Authorities have a big part to play in delivering the adult care support and also the Young Carers Statement, you are very much involved in delivering that outcome as part of the new legislation. Are Local Authorities financially fit for purpose?

PJ Thank you for that question. I think Local Authorities would say we can always do more with more money but I think for the last decade Local Authorities have been engaged in not just looking for more to do more but to get more for less. We recognise that we have to focus on frontline services, we have to make sure that everything we do is fit for purpose and that’s a journey Local Authorities have been on for a decade and it’s been tough but we recognise it is a challenge we have to continue to face because not to face up to that challenge would be detrimental to everything we care about and we do care in Local Government about delivering high quality services for our communities and we are determined to continue to do that and use our resources as best we can.

RW The next question Councillor covers really everything and covers really almost everyone who is a carer because as you’ll know, I’m...
sure, through your own experience because caring is so often focussed on the person who is in receipt of that care, the person delivering it be it a friend, relative, family member often hasn’t got the time or the resources to look at their own health so this question wants to know:

**Q** What can we put in place to encourage and enable carers to look after their own health and wellbeing and how can we highlight the fact that there is a huge impact on the carer’s health in terms of going about their daily business?

**PJ** A very good question. Gets into the real heart of what you are all trying to cope with. Well first, I have to say that clearly Local Government recognises the vital role carers play and how essential it is that you are provided with the support that you need to continue to do that. We absolutely value the input you provide and that includes your physical and mental wellbeing, and in my remarks earlier I talked about short breaks, respite and things like that. That’s pretty much where we are currently. I think we have to go further than that and one of the major challenges that Local Government is going to face is getting people across our communities actively involved, not just as recipients of services but as active problem solvers working with our Local Authorities to shape the services that come their way and I think carers are in a very strong position to be in the frontline of this. I think Local Authorities, in the years ahead, is for carers to say this is what we need; this is how we think that things could be better and for Local Authorities to co-produce the solutions to that working with you to do that. I think that’s the nature of the game, I think that’s where Local Authorities want to be and I’m pretty sure from the carers that I speak to in my own area, that they want to get involved in this to shape the things that are happening.

**RW** I was speaking to a carer who had her own health problems, in fact she had surgery and the respite care she needed as a result of that was a crisis so for her respite care was way down the bureaucratic line, it wasn’t going to be much use to her as she needed it when she needed it.

**PJ** I think that just emphasises that bureaucracy doesn’t always deliver the best outcomes for people. We really need strong local relationships between individuals and councils, and the flexibility to deliver quickly on the changes that take place. That’s why I was making comments; it’s clear that things can’t be one size fits all at National level, there has to be a strong local dimension to allow us to work more closely with the individuals and communities that we are looking to work with.

**RW** I have one final question. Why are so few carer assessments being carried out under the existing legislation and how can we assure this is done under the new Carers Act?

**PJ** Good question. I think it’s fair to say that the statistics on this might not be the most robust and you might expect me to say that. I think I can put my hand up collectively for Local Government and say our IT systems might not be absolutely good in collecting all the information to give a proper assessment of this but in some cases assessments are conducted not just as a single assessment but in a holistic way which I absolutely support, by holistic I mean the Council and the Health Service and everybody working together to deliver an assessment and sometimes if they are not recorded properly and there are a range of issues about Councils who might offer an assessment and it’s declined for whatever reason and that’s not recorded. So that’s what I mean about the statistics maybe not being all that robust but I’m also aware of carers who have asked for an assessment and have waited far too long for that to be delivered. The reason for that I think, is partly what I said about bureaucracy and Councils looking to protect frontline services rather than build up bureaucracy partly because there has been no funding to increase Councils provision for the bureaucracy that requires to be in place and I think when the Carers Act does kick in next Spring we will be looking to ensure it is fully funded so that we can do all the things that we would like to do but I suppose you can probably gather from my remarks that I lean towards more investment in the frontline rather than in bureaucracy and I think my only view is that we should be looking to deliver better quality care rather than increase our bureaucracy. That’s as diplomatic as I can put that.

**RW** Ladies and gentlemen please join me in thanking Councillor Peter Johnston.

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**Ruth Wishart**

Now if today’s about anything ladies and gentleman, it’s about trying to understand better the day to day lives of carers, your challenges, your personal circumstances and your needs.

In the first of two interviews I want to introduce a woman who is a carer for her severely disabled husband who has a high level spinal injury. Now as you might readily imagine this involves all manner of subsidiary conditions, some of which require constant attention and monitoring so the journey we will concentrate on this morning is the one she and Derek were forced to undertake as they were involuntarily moved from Disability Living Allowance to Personal Independence Payments.

Please welcome Lynn Williams...
Ruth Wishart
You’ve brought your fan club with you?!
Lynn I know a lot of this territory is tricky so I’ll try and not upset either of us but if you could briefly explain to the people in the audience who don’t know you what your domestic circumstances are and what happened with you and Derek in terms of what his condition is.

Jeane Freeman
So my husband, Derek is 68, he’s my ‘older man’ and as you can see I look very young! When Derek and I got married, Derek was already disabled so he has a spinal injury and the best way to describe that is many of you will remember Christopher Reeve who was C2 – just at the neck. Derek is T2 which means he can’t feel anything from the chest down.

With that comes a whole range of issues, one which is a risk with spinal injuries, which is something called autonomic dysreflexia...where you can’t control your blood pressure, so things like pain – you can’t register pain. When you need to empty your bladder for example this can cause a massive increase in blood pressure.

He also has osteoarthritis in both his shoulders so if you can imagine being in a wheelchair and having to do things like manual lifting and so on that becomes impossible and it now is impossible. He has osteoporosis, he broke his leg last year when transferring into the car and he had no idea he had broken his leg and found out the next day and a whole range of other conditions as well that come as you get older anyway.

Lynn williams speaks openly to Ruth Wishart about her caring role...
music, he got a thing for malt whisky, he’s into a lot of different things. He’s very funny.

RW Now you’ve been on a long journey together since marriage but you also had a career of your own and were partly involved in politics as we know and this April, this spring, you and Derek decided that this just wasn’t going to compute anymore in terms of his increasing needs and how you could operate as a unit. So just talk a bit about that.

LW We have balanced work and care for as long as I care to remember. I went part time about 5 or 6 years back. I was able to work relatively flexible around that but as the last few years have gone on, Derek’s needs have changed a lot, his mobility has vastly reduced so the things that we worked together to do have become harder. This year alone we have had something like 15 hospital appointments. We have something called hospital consultant bingo – which consultant we have not seen yet.

So it was coming to a point where it was affecting Derek because I wasn’t at home. You are balancing work, you’re balancing appointments, you’re trying to balance your work day and it just came to a point where it was virtually impossible to do that.

RW And that of course was the point where you ran into the unlovely field known as the Benefits System.

LW What that meant, many carers who have been through this journey will know this is that you’re looking at your income and what you’re earning. We were ok financially, we were coping, we happen to live in a decent area but it meant me giving up a good income, I was the main earner and basically going down to £62 a week in Carers Allowance, that’s all we were entitled to because Derek has a work’s pension so although our income is tiny we were still not entitled to anything else because of that.

RW That would affect your own sense of self-worth.

LW Yes it was funny, I knew how to apply for it, actually the process was ok, it wasn’t difficult, it was relatively quick so within about 4 weeks of me leaving work the letter came in, it was a Saturday morning and I opened it up and I just cried, I thought this is all I’m worth, £62 a week. You know I had given up my career, whatever you want to call it, it was important to me, I’m caring for my husband and I’m worth £62 a week. I just thought this is it; this is all I’m worth.

RW Let’s move on. You knew the way things were going with the UK Benefits System that he was going to be moved from Disability Living Allowance onto Personal Independence Payment. Just talk us a bit through that journey because you know you discovered this was going to happen and because of the kind of work you’ve done before went full scale into research and you got masses of information from all kinds of sources about Derek’s needs, about his incapacity and you’ve got all this up and ready for the bureaucrats but it wasn’t quite that simple was it?

LW No, I don’t know how many people have been through the DLA to PIP process. It’s a process designed to put you into living hell for a few months. We knew this was going to happen, although Derek’s 68 there was a cut-off point with PIP so if you were 65 before a certain point you had to go through it anyway. We knew it was coming so the letter arrived on 28 July this year, which I’ll never forget, I saw the envelope coming through I just knew it was the PIP letter so it comes in stages. The first stage you have to phone and start the process off and say that you want to claim so we did that. That was quite an awful phone call, it was a lady who really had no compassion whatsoever and
wanted to go through a call script. I took over the phone call because Derek, although he’s articulate he hates being on the phone and he struggles with information sometimes so we got that process out, the form came out and it’s a 40 page form and it’s not an easy form to fill in and you have 4 weeks to fill it in. So basically within that period you actually only have 2 weeks to do that because you’ve got to get it back in time otherwise you lose your benefits so you have to get it back within that 4 weeks so within that period I had to speak to as many consultants and doctors as I could to gather as much medical evidence as I could. I had been researching this and there’s a lot of great websites out there, one of which is the Benefits and Work website which was set up by ex DWP staff and it takes you through the process stage by stage, what they’re looking for, what counts, all of that so I was able to speak to consultants and say “look we need to know the impact of Derek’s conditions”.

We have two fabulous consultants, one in the spinal unit who has known Derek for 30 years and did an amazing letter which really brought home to us how much Derek’s needs had changed. The first 2 pages were his diagnoses and then the rest was the impact. We got a great letter. Derek had a stoma fitted last year for bowel problems which I won’t go into and he did an amazing letter which talks about the psychological impact and then we spoke to our GP who was incredibly supportive but charged £40 for the letter.

RW I find that quite extraordinary.

LW Yes the receptionists who are wonderful were mortified but £40 was a lot of money when you have a limited income but we had to have as much evidence as possible and I also spent weeks going through the questions, gathering information on his conditions plus those that support you, what the impact of the conditions are. I mean this process goes into the most intimate parts of your life which include how do you go to the toilet, having to describe that. It’s just it goes into every part of your life basically to see if you’re disabled or not.

RW The thing that struck me when you and I had a blether about this on the phone the other day, and the thing that struck me about all this is that you were, if you like, internet literate. You know that you knew where to go to get the answers that you needed. Because of that website, you knew which consultants you needed to see, what questions they’d need to know and how to respond. But there are a lot of people who haven’t got that background knowledge or haven’t got the time or the energy to do that and I’m wondering how they think somebody without your very impressive energy could have got through this.

LW It’s funny because Derek and I have spoken about this a lot and before I answer that question I’ll quickly go back to a few weeks back. We were sitting and at this point we had been through all the process, we had the face to face which is a whole other story and Derek just broke down and we were having lunch and I just saw him out the corner of my eye and he was crying and I said, “What is it?” and he said, “I can’t face this anymore Lynn”, he said, “I can’t go through this”. So all of this is going on and I was able to do all this, all this research and he said “Lynn, I couldn’t have done this without you”.

If it had been me on my own I would have stopped and would have said, keep your benefit because I couldn’t have gone through the evidence gathering, fill in the form, the face to face which was horrific so all of this, I’m lucky because my previous
job, well part of my job, was Welfare Reform and I knew where to start so for those who are struggling it’s that navigating who you go to for support and where do you start. Some people just struggle through it and they lose sadly.

RW Let’s go on with the face to face because my understanding of the new devolved legislation will be that if you provide the amount of evidence that you’ve provided that you shouldn’t have to have a face to face but that point hasn’t been reached yet so tell me briefly if you can because I know it has been horrendous, tell me briefly if you can about that interview and the impact it has had on both of you.

LW My aim in the process was to avoid the face to face because I knew Derek would struggle with it and they didn’t manage to do that. There was a whole bit behind it with ATOS not doing their job properly. They have now actually admitted fault to us because Derek had enough medical evidence there for them to do what they call a paper based assessment. They didn’t do that, they ignored it, despite me asking them twice to look at it. So eventually we had to do this face to face which was in the house and I was surprised as I thought I would have to fight to have it at home so it was at our home. We had a phone call saying, my understanding was there was only one person coming out to see us, what they call and I’ll use this in a ‘health professional’ coming out to your house and two people appeared, I had no idea who the second person was. We asked her who she was and I asked, “Are you here for training?” and her response was, “Yes, something like that”. She sat in my house with my husband and said nothing for the whole hour. Face to face basically, from the minute the lady came into the house and convinced her agenda was to reduce Derek’s benefit because she under plead his disabilities, she under plead his abilities, she under plead my role as a carer and at one point I was describing what I do for Derek in terms of catheterisation, you know emptying things and so on and she said well your job’s just lifting and laying then. I thought well you’re kind of missing the point here. She got out the house alive but the point is, for me who understands the system, I was not as assertive as I would usually be, you’re kind of scared to rock the boat. Derek and I were both terrified if we rocked the boat that we would end up with nothing so we looked at how she asked the questions and I had now looked at the scoring where she was asking the questions and where we scored less. For those of you who know PIP there’s two parts mobility and Derek scored 0 for planning a journey and taking a journey. Derek can’t go out without my support, we’ve got a car lift in the car and we got a 0 for that. She gave I think 2 points for washing and dressing, Derek can’t get dressed.

RW What you seem to be saying is that the game plan of the ATOS official was to minimise the payment that would have to be made.

LW Absolutely. At the time I thought I was mishearing things and I was listening to what she was saying, I’m convinced the way she was asking the question was to minimise the payment. The more I think about it now and now I’ve seen the scoring and compare the role is either to put you off and then to reduce your benefit. I’m not a conspiracy theorist believe me but that was my personal time it was horrific. Derek felt that he had failed a test he didn’t actually understand. You don’t know why you’re being put through what you’ve been put through and you don’t understand why they are asking questions. They did a kind of medical exam of Derek. Derek can’t move his arms or shoulders and I had to say, “Why are you doing this? What are you doing this for?”

RW The Minister responsible for the new Social Security arrangements has gone to another engagement but we know where she lives. So if you had to give her a message from today, from someone like you and there are lots of people like you listening. If you had to give a message that we can pass on, what would it be?

LW Some of the stuff that’s come out, I’ve watched the Minister as you probably guess I’m a bit of a policy geek, I kind of watch this stuff
in my spare time so I have watched her and she’s very impressive and there’s a lot of good language coming out but dignity and respect don’t pay your bills, so you can have the system as dignified and respectful but at the end of the day you’re still on a crappy income. Good language is fine and the direction of travel is very positive and we keep hearing about what we can’t do because we don’t have enough money to do these things. Well carers you know save the Government £11b a year and Mr McColl, I think is his name, has said this system would collapse without our support. My message would be, be ambitious, you know find the money. I think the choices that we make are political and that we can choose to either give people a decent income and that includes my husband who worked all of his life. That shouldn’t matter, people contribute to society in different ways, and people should be valued in where you are and as part of your family. My husband shouldn’t have to prove his worth as an individual and that’s what he’s had to do and my message would be, be ambitious, and find the money. If I was asked to pay more tax just now to make sure we could have a better system I would do it on my Carers Allowance so if I’m willing to do that maybe others are too. Just to listen to what people are saying, carers are at breaking point in that many of you across the country who are struggling with a lot of bureaucracy. I’ve been told no, I’m fighting council systems for the tiniest bit of support. It’s time to get our heads out of the sand and pretend that everything is fine. Things aren’t fine and I know that I am struggling, we are about to look at Self Directed Support process and I’m about to tell my Council to get stuffed because I can’t face the bureaucracy, I can’t face the assessments and I can’t face someone else coming into my house and just looking at what we’re doing. It’s time to start listening to what we’re saying.

RW Ladies and gentlemen I want to thank both Derek and Lynn Williams. A great loss to politics but not to Scotland.

Ruth Wishart

Now ladies and gentlemen you are going to move to the facility to discussions shortly, I think there are ten of these and you signed up for which one of these ten you are going to attend.

The next two hours including lunch, where you can share and learn from each other’s experience and we’ve got to guide you through this process so let me introduce [Fiona Collie and] Graeme Reekie....

Fiona Collie

I don’t know if folk can hear me ok, in your packs you have a list, it’s a coloured sheet, it’s about three pages and it tells you what workshop you should be in and the tables have got names on them. I know most people are at the right table but you can move to the correct one if you’re not. We’re slightly behind so we are going to go on maybe until about 12:25/12:30 and then we will come back here. Graeme Reekie will come and explain a bit more about the next session in the sharing and experience. If you can just check where you should be and move about and a couple of the workshops are in the breakout rooms with the workshop facilitators. Thank you.

Ruth Wishart

Thanks Fiona. Ladies and gentlemen I wonder if I could have your attention for a minute, Hi there, I think I’ve said this already by accident earlier but I mean it this time for the next two hours including your lunch there’s going to be a whole myriad ways in which you can share more of your experiences across the groups as well as those you have been spending the last 45 minutes or so with. But it’s slightly more complicated than that, far too complicated for a brain like mine so the man who is going to guide you through the whole process is Graeme Reekie....
CONSULTATION ZONE WORKSHOPS
Hi there, thank you for having me. I’m conscious that there is still one workshop to join us so I’ll just gradually introduce the plan that we’ve got for the next couple of hours.

So I’m Graeme Reekie and I was involved in the Steering Group that was planning the event and when we were planning the event a lot of us are allergic to conferences and allergic to being talked at so hopefully you will already feel that you’ve had space and time to talk to each other and to share experiences because that’s likely to be the most important thing that you do today.

So what we’ve planned into the day now and we won’t apologise for it, hopefully it’s a good opportunity, plenty of space and time, so between now and 2:20pm assuming you don’t want lunch you could actually have an hour and 50 minutes to do the things I’m going to invite you to do.
You can also squeeze in lunch there if you want to, space and time to talk to each other and share ideas. There’s three ways we are going to invite you to do that. Very shortly you will exit through this door here or this one there and what you will find there is a marketplace of ideas where there will be stall holders with lots of information that’s hopefully relevant for you and you’ve got the opportunity to talk to them and find out more about their services. Then you also have the opportunity to share your experiences with each other and with the organisers of the event. The ways that we will do that, if you imagine that this wall is see-through, if you look over there to your right hand side along the bottom of the room in that direction, just past where the food will be at 1:00pm. Over there is something called a wishing wall and you’ll have seen something like this before, it’s sometimes called a graffiti wall and the idea is you just record your hopes, wishes or aspirations for yourself as a carer or for other carers, it’s as simple as that. A wishing wall, you write directly onto the wall, you can write on post-it notes if you want to but you can also just write on the wall, we won’t be using it again so feel free to just fill it with notes, doodles, drawings and words.

Moving this way some of you will already have spotted what somebody has called the model village, a table that looks just a bit odd, yes a model village, it wasn’t called that before today but it’s what you’re calling it, it’s what it’s called.

There’s a model village and the question we would like you to answer with is – Imagine a Carer Friendly Community and what it would look like, what a Friendly Carer World would look like and your invitation here is to draw and write on anything that is on the table, there’s buildings there, there’s people there, there’s roads. Fill it up please with drawings, words and ideas, what a Carer Friendly Community would look like. It will make sense when you see it, honest. Then if we move left again the one nearest this door, there is the opportunity to share feedback from the workshops that you’ve just been in. The only thing I want to stress here is it’s not an evaluation so you can tell us what you thought of the workshop and that’s fine. What we’re hoping to use this one for is an opportunity for you to say something that maybe you didn’t say around your tables. Please share your comments and thoughts on the workshops that you have been in. However, there’s nine other workshops that you’ve not been in so what we hope is if people share their feedback and ideas from the workshops you can then go and learn what was happening in the others. So as I said not evaluative comments as such but sharing the ideas, sharing your comments and thoughts on the topics that were being discussed in those workshops. So can I just have a quick nod? Does that roughly make sense? Marvellous and thank you.

There’s also the opportunity at that station to contribute to the consultations that the Minister mentioned earlier so we have some consultation questions on the changes to Carers Benefits and Social Security and hopefully, I’ve not discussed this with them so apologies in panicking you but if you’ve been running the workshops on those themes I’m hoping the workshop facilitators will be around to talk to you and to answer your questions and to encourage you to take part in the consultation. I think that’s pretty much it, as I say, if you see it, write on it, it’s your space and it’s your time, we have until 2:20pm, lunch is served at 1:00pm, so take the opportunity to talk to each other and share your experience with us and with each other, speak to our stall holders, squeeze in a bit of lunch if you must but otherwise there’s plenty of work for you to crack on with between now and then.

As I say, you can exit out of this door here and this door here and I will see you in the model village. Enjoy everybody, thank you.
CONSULTATION ZONE REPORT

By Graeme Reekie

SUMMARY AND OVERVIEW

During the Carers Parliament 2016, three ‘consultation zone’ activities asked carers to share their views on their wishes for the future; carer friendly communities and parliament workshops.

In total over 300 separate comments were shared. Clear themes emerged within each activity, summarised below. There is an interesting amount of consistency between the themes, indicating that core issues have been identified.
CORE ISSUES

CARERS ALLOWANCE AND WELFARE REFORM
Several people expressed the view that Carers’ Allowance should be benchmarked to wages not benefits, and should continue during study and retirement. Applications and assessments were seen as unnecessarily burdensome.

APPROPRIATE SERVICES FOR CARER AND CARED FOR
There was a clearly expressed desire for easier access to carer support services, and for care services to include carers as partners. Quality of care for supported people improves outcomes for carers.

RESPECT AND UNDERSTANDING
Simple things can help to create a more ‘carer friendly’ world. Supportive services play a big part, as do understanding communities.

ACCESS TO TRANSPORT
Free or concessionary transport for carers to get around was a recurring theme.

EDUCATION
Suggestions to improve education for carers included universities making allowances where caring impacts on exam results; using Young Carer cards to encourage disclosure to and support from schools; and putting the subject of caring on school curricula.

EMPLOYMENT
Greater flexibility in work can prevent carers having to give up work. Supported returns to employment would also be welcomed.

HOUSING
Affordable, accessible housing is an important part of a carer friendly community.

RESPITE AND SHORT BREAKS
As well as needing breaks, carers described needing clarity about their entitlement to them. Tailored breaks were desired for retired carers and young adult carers.

YOUNG ADULT CARERS
Greater recognition could be given to the unique status and challenges of being a young adult carer.
CONSULTATION ZONE ACTIVITY 1: WORKSHOPS SHARING LEARNING

In our first Consultation Zone activity, people were invited to share learning from the morning workshops they had taken part in. They could also contribute comments on each of the other workshop topics.

**KEY THEMES**

Seven common themes emerged from participants’ workshop notes:

1. Income parity – and continuity through life transitions
2. Single points of contact for carers
3. Easier mental health access for carers
4. The negative impact of applying for financial support
5. The need for early planning
6. Uncertainty and anxiety faced by carers
7. Support and understanding in employment and education

Each theme is illustrated with participant quotes below.

Full notes from each workshop are shared in Appendix 1.
THEME 1:  
INCOME PARITY – AND CONTINUITY THROUGH LIFE TRANSITIONS

‘In education you get a bursary not a wage. It should not bar you from receiving Carers Allowance.’

‘Carers Allowance stops when I’m 65. Pension starts when I’m 67. How about some fairness?’

‘£8.25 an hour for carers – all carers. We need a living wage! No more rhetoric about Carers Allowance now being equal to Jobseekers – disgusting!’

‘Carers Support Plan should unlock carers’ budget in SDS, but not to reduce the cared for’s budget.’

THEME 2:  
SINGLE POINTS OF CONTACT FOR CARERS

‘Single point of contact in health services – a ‘carer aware’ person.’

‘Health, social care and education need to make ‘working together’ a fact rather than fiction. One person contact for carer would be ideal.’

‘Council social work departments – should have a person on their staff who is completely independent of the local authority but who has knowledge of the services’ systems which need to be negotiated when someone is a carer.’

‘Need a single point to call about all benefits. They then direct you to correct department or help that you need.’

THEME 3:  
EASIER MENTAL HEALTH ACCESS FOR CARERS

‘If you are the one and only carer for someone, you need to know you can contact someone if you have an accident or become ill. What is in place in Scotland in the 21st century?’

‘Carers looking after profoundly disabled individuals need very quick (fast track) access to mental health services. Too many carers now on anti-depressants due to caring role.’

‘Better support for carers in this area – access to support/programmes to maintain positive health and wellbeing and easy to access interventions when health and wellbeing deteriorates.’
THEME 4:
THE NEGATIVE IMPACT OF APPLYING FOR FINANCIAL SUPPORT

“What is the purpose of the system? Is it to help people gain support or to prevent them claiming? If it is to ‘help’ then forms, claims procedures need to be reflect this. Current system feels like it’s designed to prevent successful application for social security.”

“The DLA forms are long and difficult to fill in. All it looks at are all the negative aspects – completing it for my child is distressing. Why do I have to go through this again for PIP?! His condition is lifelong.”

“Made to sell your child as is they are of no value. DLA forms are degrading and harrowing for parents to fill in. They are precious children with a disability. We ONLY apply for benefits to help them have a good quality of life.”

THEME 5:
THE NEED FOR EARLY PLANNING

“Schools need to listen and involve parents more in decision making. Carers of profoundly disabled children should be advised of transition planning in written form and it should be made clear when this should start.”

“Hospital discharge planning should start on admission and must involve carer from outset.”

“Exams – it is not clear what level of exam support will be put in place for disabled until exams are right on top of you. Support arrangements should be put in place at start of curriculum, not just when exam arrives.”
THEME 6:
UNCERTAINTY AND ANXIETY FACED BY CARERS

‘I speak to many carers with young children with disabilities and they are incredibly frightened for what the future holds. Lack of help, lack of support, no straightforward way to access information. Many have lost their own identity and don’t know how to be a ‘person’ again.’

‘Carers mental health suffers due to an uncaring system. The stress of the ‘brown envelope’. Not knowing if arbitrarily being called in for re-assessment and if financially this will break you.’

‘Worrying about future careers. Worrying if your loved one would cope without your help. Not knowing what to do for the future. Not having a plan. Not knowing what classes to take.’

THEME 7:
SUPPORT AND UNDERSTANDING IN EMPLOYMENT AND EDUCATION

‘We should learn from ‘carers leave’ in Ireland – time off for caring responsibilities with your job being held for you to return to – similar to maternity leave (with financial support to do so).’

‘School not knowing why attendances is so low. Not getting a chance to explain why. Homework struggles and getting distracted in class due to worrying about the one you care for.’

‘Look at how carers can be supported (i.e. if lower grades) to get placements in educational establishments i.e. if they are carers they get an interview and caring impact is taken into account.’
The next Consultation Zone activity invited participants to ‘build a carer friendly community’ using paper buildings, roads, vehicles and people.

The imaginary community (renamed ‘The Model Village’ by participants!) was originally sectioned off into four areas:

1. Services
2. Employment
3. Education
4. Leisure

People used the space more creatively, making lots of links and crossover between the areas.

**KEY THEMES**

The main themes to emerge are listed in the tables below with illustrative quotes. The notes are given in full in Appendix Two.
<table>
<thead>
<tr>
<th>THEME</th>
<th>NO. OF COMMENTS</th>
<th>ILLUSTRATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Built environment &amp; accessibility:</td>
<td>22</td>
<td>‘Access to public parks needs to give access to all. If a wheelchair user can access it, so can pretty much everyone, but currently too many barriers.’</td>
</tr>
<tr>
<td>Physical access</td>
<td>6</td>
<td>‘Better design of streets to make them accessible to all. Lighting, drop kerbs, contrast between road and pavement, grab rails.’</td>
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<tr>
<td>Green spaces</td>
<td>5</td>
<td>‘Adult changing facilities in disabled toilets.’</td>
</tr>
<tr>
<td>Access to toilets and changing</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Access to transport:</td>
<td>18</td>
<td>‘All carers should receive a discount or concession on public transport to enable the carer to do some of their caring duties easier and quicker.’</td>
</tr>
<tr>
<td>Free transport for carers</td>
<td>10</td>
<td>‘Integrated transport to include wheelchair users and covering all rural areas.’</td>
</tr>
<tr>
<td>More accessible transport</td>
<td>3</td>
<td>‘More inclusive cycling, like Glasgow’s Freewheel service.’</td>
</tr>
<tr>
<td>More rural transport</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Appropriate services for carer and cared for</td>
<td>15</td>
<td>‘Social work to work on outcomes not budget.’</td>
</tr>
<tr>
<td></td>
<td></td>
<td>‘Support in home not at expense of traditional services.’</td>
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<tr>
<td></td>
<td></td>
<td>‘Health and wellbeing hub for all community, on a high street or central location.’</td>
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<tr>
<td>Education</td>
<td>11</td>
<td>‘Schools consider having a young carer class as part of curriculum example – Wallace High School.’</td>
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<td></td>
<td></td>
<td>‘Using my Young Carer authorisation card in school to get support.’</td>
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<td></td>
<td></td>
<td>‘Going Higher campaign <a href="https://carers.org/going-higher">https://carers.org/going-higher</a> ’</td>
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<tr>
<td>Employment:</td>
<td>18</td>
<td>‘More advice and help for ex-carers making the transition back to employment.’</td>
</tr>
<tr>
<td>Employer support</td>
<td>10</td>
<td>‘Employer to allow time off work so you can go to appointments with the person you care for and not</td>
</tr>
<tr>
<td>Help getting into employment</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Funding care and carers</td>
<td>9</td>
<td>‘Outcomes to be met, not budget.’</td>
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<tr>
<td></td>
<td></td>
<td>‘Increased carer support, not decreasing it!’</td>
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<tr>
<td></td>
<td></td>
<td>‘Free personal care for all not just for over 65s.’</td>
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<tr>
<td>Carer inclusion</td>
<td>9</td>
<td>‘Treating carers as equal partners in care.’</td>
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<td></td>
<td></td>
<td>‘Look at bigger family picture as often everyone is caring.’</td>
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<td></td>
<td></td>
<td>‘Carer should be made aware of any decisions made, not just ‘next of kin’.’</td>
</tr>
<tr>
<td>Respect and understanding</td>
<td>9</td>
<td>‘Respect me as a carer – I live my principles.’</td>
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<tr>
<td></td>
<td></td>
<td>‘Everyone, no matter the profession, would have training to deal with additional needs (physical and mental) therefore as a carer we would run into fewer ‘judges’.’</td>
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<tr>
<td></td>
<td></td>
<td>‘Education, nurses, doctors, social work, teachers – walk in my shoes.’</td>
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<tr>
<td>THEME</td>
<td>NO. OF COMMENTS</td>
<td>ILLUSTRATION</td>
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<tr>
<td>Support from communities</td>
<td>9</td>
<td>'Neighbourhood Watch-type communities – local volunteers who can lend a hand every now and then.'</td>
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<tr>
<td></td>
<td></td>
<td>'It is as simple as being made to feel welcome! Smile :)'</td>
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<tr>
<td></td>
<td></td>
<td>'You could go to a public space e.g. a café and go to the toilet and someone would watch your cared for person for 5 mins.'</td>
</tr>
<tr>
<td>Quality care</td>
<td>8</td>
<td>'Carers and those being cared for want normal life in community. Care in home is not what it should be.'</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'We need reliable friendly on time, constant care from social services.'</td>
</tr>
<tr>
<td>Finance and Carers Allowance</td>
<td>8</td>
<td>'Education is a right and so is Carers Allowance! Should get both.'</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'Carers allowance should not stop when carer comes to retire as caring role does not stop, in fact it gets harder. Old age pension is not a benefit, it’s paid for!'</td>
</tr>
<tr>
<td>Hospitals</td>
<td>6</td>
<td>'Look at the Barra Unit in Royal Ed Edinburgh. They know how to action transitions successfully.'</td>
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<tr>
<td></td>
<td></td>
<td>'Hospitals that have wards that would not be detrimental to people with dementia.'</td>
</tr>
<tr>
<td>Leisure</td>
<td>6</td>
<td>'Good changing facilities in pools.'</td>
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<tr>
<td></td>
<td></td>
<td>'A sports centre that offers carers a budget access scheme so that they can go and exercise on their own for their own benefit – which benefits their cared for.'</td>
</tr>
<tr>
<td>Town and area planning</td>
<td>6</td>
<td>'Schools near to homes so young carers can easily go home if needed to check on those they care for.'</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'Community council – area plans, support carers and the ones we love.'</td>
</tr>
<tr>
<td>Housing</td>
<td>5</td>
<td>'Paying a mortgage on Carers Allowance is difficult. More affordable housing required.'</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'More housing with disabled access.'</td>
</tr>
<tr>
<td>Carers’ wellbeing</td>
<td>5</td>
<td>'My health matters! My mum would hate to think my love for her made me ill and lost job :('.</td>
</tr>
<tr>
<td>Respite/breaks</td>
<td>5</td>
<td>'As an employee I am entitled to 5-6 weeks paid leave. As a carer please consider at least 5-6 weeks respite.'</td>
</tr>
<tr>
<td>Psychological accessibility</td>
<td>4</td>
<td>'Quiet areas for carer and cared for person.'</td>
</tr>
<tr>
<td>Young carers</td>
<td>3</td>
<td>'Funding for young carers (not just 16+)'</td>
</tr>
<tr>
<td>Benefits</td>
<td>3</td>
<td>'Assessments that work with the disabled people, not against them.'</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>'What helps the cared for – help the carer!'</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'Safe!'</td>
</tr>
<tr>
<td></td>
<td></td>
<td>'Post care psychological support for carers.'</td>
</tr>
</tbody>
</table>
CONSULTATION ZONE ACTIVITY 3
THE WISHING WALL

The final Consultation Zone activity was a ‘Wishing Wall’ on which people wrote their responses to the question:

‘If you had one wish for the future, what would it be?’

KEY THEMES
Similar themes emerged to those in the workshop zone and ‘model village’:

• Education support
• Quality care
• Employment support
• System change
• Carers Allowance
• Funding
• More awareness of carers issues
• Income
• Concessionary transport
• Support for Young Adult Carers
• Respite and breaks
• Involvement
• Benefits

This consistency is interesting: the Consultation Zone results indicate that there are a number of core themes that matter to carers.
<table>
<thead>
<tr>
<th>THEME</th>
<th>NO. OF COMMENTS</th>
<th>ILLUSTRATION</th>
</tr>
</thead>
</table>
| Education support             | 10              | ‘Student carers should automatically receive a bursary as often parents income is spent on caring, no matter to what level. Carers Allowance too.’  
                              |                  | ‘A chance to get into uni with lower grades if we do well and we are on track.’  
                              |                  | ‘An appropriate education for all children in Scotland, regardless of level of need (instead of 7 years of fighting and still no education).’                  |
| Quality care                  | 8               | ‘Better care in the home provided by the council.’  
                              |                  | ‘Good outcome for cared for person is what makes biggest positive impact on carer.’  
                              |                  | ‘(I wish) My daughter was well looked after with stimulating activities in place, and cared for as well as possible in the community and provide passionate care so I could die in peace.’ |
| Employment support            | 7               | ‘More support for working carers getting back to work.’  
                              |                  | ‘All H&SCPs and councils and TSIs and care providers to be Carer Positive’                                                                                                                                  |
| System change                 | 6               | ‘End the postcode lottery.’  
                              |                  | ‘Make the system suit carers and cared for rather than those people trying to fit in the system.’                                                                                                          |
| Funding                       | 6               | ‘Support to meet outcomes and not to be a financial cost.’  
                              |                  | ‘Funding for Young Adult Carers.’  
                              |                  | ‘We need funding and services put in place. Care Act is a waste of the paper it is written on without money to back it up.’                                                                                      |
| Carers Allowance              | 5               | ‘A carer is not my identity, it is part of my life. Carers Allowance doesn’t recognise or reflect this!’  
                              |                  | ‘Carers Allowance to be equal to Living Wage – we are not unemployed, our job is caring.’                                                                                                              |
| More awareness of carers issues| 5               | ‘Social work staff to be more aware of situations!’  
                              |                  | ‘Agencies to listen.’                                                                                                                                                                                     |
| Income                        | 5               | ‘A pension I can live on and not in poverty because of caring role. Prevents me adding to my work pension.’  
                              |                  | ‘More money for carers commensurate with the job they actually do, and save the NHS and social care budgets.’                                                                                             |
| Free transport for carers     | 5               | ‘Fee/resourced travel, Scotland-wide for carers.’  
                              |                  | ‘I wish for free/concessionary public transport for carers of all ages.’                                                                                                                                   |
| Support for young adult carers| 5               | ‘Recognition of young adult carers, not as a young carer, not as an adult carer.’  
                              |                  | ‘Listen to young adult carers need for local services.’                                                                                                                                                   |
| Respite and breaks            | 5               | ‘More support with respite care and breaks.’  
                              |                  | ‘Easy access to breaks for carers.’                                                                                                                                                                      |
| Involvement                   | 4               | ‘Genuine partnership between professionals and carers. Carers know the cared for person they are expected to pick up the pieces when the system fails.’                                                                 |
| Benefits                      | 3               | ‘No more fear of brown envelopes.’                                                                                                                                                                          |
OTHER COMMENTS:

In addition to the themes that emerged above, 18 other answers were given:

‘To make it another year.’

‘Seeing the disabled as valued people.’

‘Proper recognition of the role carers play both financial and attitudinal.’

‘Better support for LGBT carers in community.’

‘Get support right for the carers for everything else will follow.’

‘More schemes like Partners at Newcastle Uni.’

‘Lots more support for carers.’

‘Free holistic treatments at training colleges for health and beauty students if you volunteer as a model/guinea pig.’

‘First we shoot all the lawyers.’

‘To know my disabled child would have a safe, happy future and adulthood.’

‘To be appreciated.’

‘What is the balance between individual, community, professional, voluntary, local government, national government?’

‘To see people are people, not just cases or stars.’

‘What is reasonable when there are so many competing priorities?’

‘Open dialogue’ website for all MH carers.’

‘No discrimination and no racism – we are all the same!’

‘More support groups for carers.’

‘Support young children with special needs.’
REPORT OF AFTERNOON SESSIONS
Ladies and gentlemen could you please take your seats so that we can get started, thank you. Okay ladies and gentlemen we will get underway with the afternoon. Thank you very kindly.

RW have had a lot of conference lunches in my day as you can see from my shape and that was one of the best, I hope you all enjoyed it.

Now I did say ladies and gentlemen at the beginning of the day we had a number of distinguished guests joining us in this our 5th Carers Parliament and one of them is a woman that proves imitation is the sincerest form of flattery because after being at one of our Carers Parliaments, she went back and set up her own version in Finland. She is the Chief Executive of the Central Association of Carers in Finland and vice Chair of Euro carers so please give a warm Scottish Welcome to Marja Tuomi.

**Marja Tuomi**

Hello. Susanna Saanikari and I are both from Helsinki that’s the capital of Finland. Susanna is the main carer for her son. She and I were introduced due to my role within the Central Association of Carers in Finland and also a member of the Committee of Euro Carers. I bring you very good wishes from my colleagues. I must say that Susanna and I are very happy that we have an opportunity to attend this Parliament and I want to thank you both VOCAL and the Scottish Government for your kind invitation.

Three years ago, two colleagues of mine attended the 3rd Carers Parliament in Scotland. They
returned full of inspiration and thought of the idea of organising a similar event in Finland.

We all liked that idea and I’m happy to tell you that last year in August we had the 1st Carers Parliament in Finland.

The Parliament was very successful, we had 250 carers and representatives from our local associations, from other organisations, also some International guests including Sebastian Fischer from VOCAL. We too had Government Ministers speaking and answering questions of carers. Many of these questions were similar to those we have discussed today here, carers support, carers help, financial support, better services for carers, more breaks and regular holidays.

The challenges carers face are similar all over the world and not surprisingly also the pressures and the demands carers have, there are also demands on politicians are similar but we didn’t know until we started to discuss with each other and meet carers from other countries we can learn from each other, we can copy your good experiences and change experiences. Yesterday we had a meeting with our colleagues from Ireland, Germany and Portugal. One of my colleagues from Ireland, a carer also, she said that she feels these kind of meetings are very empowering. It is true, it feels very empowering to be a part of such International solidarity. Tomorrow Susanna and I are going back to Helsinki and we are again taking back much of which we have learnt today here. From our discussions today and yesterday with our other European colleagues, this time I will take with me this concept. I am confident we can strengthen these links and conducts over the years to come for the carer and more care in Europe.

Once again I want to thank you for welcoming us so warmly to Scotland. Thank you.

Ruth Wishart

Now there’s a bit of excitement here ladies and gentlemen, our next interview with a carer, I hope is going to be with Catriona McRoberts...
Carers Parliament 2016 Report

Ruth Wishart

Catriona McRoberts like many carers has run into logistical problems today and can’t be here in person, we hope she’s on the other end of a Skype line but the mixture of Skype and technology generally and myself has never been particularly fruitful in the past but hey we have half of Cat, we’ve got all of Cat. Can you hear me Cat?

Catriona McRoberts

Yes I can hear you Ruth.

Ruth Wishart

Well thank you very much for wrestling with your laptop. It will save me having to wrestle with mine. Let me just say, Cat has three children, one of whom, is severely autistic and she also has responsibility for her mother, who has dementia and despite all of which she is looking in remarkably good shape. Please welcome, albeit on a line, Cat McRoberts.

I’ve touched briefly Cat on your family circumstances but can you tell us just a little bit about your domestic situation and where you are at the moment.

Catriona McRoberts

Yes I’m mum to three children and their ages are 15, 9 and 8 and as you said my 8 year old has autism and learning disabilities and extremely challenging behaviour. My mum has vascular dementia, and fibromyalgia. I’ve been the primary carer for my mum since my dad passed away 8 years ago and dual carer when my third child was born with health difficulties and then we discovered he had autism as well though I’ve just been juggling with that since 2008.

Ruth Wishart

Now I know we had a bit of a chat the other day on the phone and you were telling me about your youngest there, your autistic boy and it’s not just a question of communication difficulties he’s actually quite a disruptive presence isn’t he?

Catriona McRoberts

Yes, Kieran has extreme, violent tendencies, aggression, violent behaviour, he attacks us all on a daily basis, he attacks the home, he breaks furniture, he boots down doors, he’s extremely angry and he’s quite a big boy for his age as well. He’s only 8 but he’s probably the height of a 10 year old and quite large built as well so to restrain him, to calm him is really difficult.
on both myself and my husband who are both getting older, we’re not getting any younger and we have sleepless nights as well and basically our house is not a home, it’s fractured, it’s almost like a war zone on a daily basis where we try and repair physical damage but we can’t really get any respite to repair the mental and physical emotional damage on ourselves and in particular, I’m finding it extremely hard to keep both my sons safe. My middle child, Logan is only 18 months older than my autistic son, he is always being spat on, verbally attacked, physically attacked and it’s a shame because he’s been brought up in this environment not thinking it’s any different so he’s also been susceptible to bullying at school because he thought it was normal to be attacked and to be hit despite our best efforts to tell him this is not a normal environment. My daughter’s quite lucky because she remembers the days before Kieran was born that our home was a lovely wee place but we just got to that situation due to Kieran’s autism.

RW One of the saddest things you told me about Kieran was that although he has no particular control over his violent outbursts and his violent behaviour towards his family and towards other people that what he does have after the episodes are over is a terrible remorse.

CM Yes he wants to be a good boy. I think sometimes he attacks Logan because he sees Logan being maybe what he would like to be, normal and calm. Also Kieran can’t go out, he can’t go out to play and when he sees his brother going places, Kieran questions why can’t he go out to play. It’s because I have to keep him safe and keep others safe from him but in the same respect Kieran is entitled to a childhood, he is entitled to play but we can’t give him that.

RW Tell me how you got on when you tried to access some support from Social Services for both the situation with Kieran and with your mother?

CM Predominently I hit closed doors all the time, I have begged for additional respite for Kieran and for us, Kieran only has 4 hours respite a fortnight with Cosgrove Care, I couldn’t even get respite within my Local Authority when he was 31/2.

RW Can I ask you Cat if you’re only access at that time, 4 hours a fortnight, presumably an adjoining Local Authority and not your own – was the travelling time taken off these 4 hours?

I’m going to stop you just for a minute Cat because I’m not sure if the audience is picking you up. I don’t know Phil if you can give Cat some instructions to maybe get nearer the microphone.

CM Let’s move on if we may because I know that in the midst of everything else that’s happening in your life, you’ve been been very much involved in setting up help for other families with autistic children. Tell us a bit about Autism Triage Scotland if you would.

CM Well it just came about because I found myself going about different workshops and meetings and I used to meet lovely people along the way and try and share information and then I was at one conference at the Hope Centre, Airdrie and it just came to me, Jane Porter from Scottish Autism was up talking about something and there was various other great speakers there and I just looked around the room and thought look at all these people sitting here who are getting this information but the people who can’t come to conferences for whatever reason or miss them or don’t know they’re on or are too tired with their caring roles to take over. I wanted to create a platform where we all came together so that’s carers, autistic individuals, MSPs, therapists, ASN teachers, support teachers, anybody who is involved in the network of autism within Scotland and bring us together under one platform called Triage Scotland...

We now have about 1600 members.
where you are in your career, if you had a career at all. Everybody’s situation is completely different of course, everybody’s aspirations but I just feel within the employment sector carers are not recognised or understood at all. It’s discrimination, it absolutely is and I don’t use that word lightly because I don’t really like it but we are discriminated against. You may well go along for an interview and you may well tick all the boxes and be that right person and if you are offered that job sometimes you can’t accept that job, that’s horrendous because of your caring situation.

We have got so many services in Scotland, we’ve got support everywhere across Scotland but we are not getting access to it, why not, why are we denied access to services that are set up to support us, to help us in our role, to allow us to function in society, to earn money to live to keep your home.

Why are we always put aside as being unemployed and not useful and everything, we’ve got great carers who are qualified in all sorts of levels across Scotland and I just feel lucky I am in employment. Thank goodness, Hamilton Accies Football Club have got a caring and responsible attitude towards carers in their role and respect carers, respect the fact that they can’t come in some mornings for 9:30 or 10:00 perhaps because that parent’s been knocked from pillar to post by their child trying to get ready or they’re exhausted from being up all night but you know flexible working terms where you could maybe start at 11 that day an finish at 2 and work a wee bit from home.

We are now in such a society where we are Skyping today, there are so many options out there and I think it’s time the Scottish Government looked at employment seriously for carers across Scotland because we are growing into a community where carers are, sandwich carers, dual carers, looking after your elderly parents, looking after your own children. This has to be addressed.

**RW** Cat I just wish that I could have met you in person, I enjoyed talking on the phone, I loved talking to you today and you’ll want to know there’s a Government Minister in the audience today and I’m sure she was fascinated by all that as well. Thank you so much for making the effort to join us.

**CM** Thank you.
“Thank you very much Ruth and it is a privilege to join you here today at the Carers Parliament and of course to hear from Cat earlier and of course the work she is doing locally, not too far away from my own constituency in Clydesdale.

Today though I wanted to start with an inspiring quote that I once heard, that said never believe that a few caring people can’t change the world for that’s all who ever have. The reason I thought that was particularly apt is because this gathering of carers, this Parliament over the last five years has dramatically changed the landscape of legislation and activity across Scotland and given the international representations here today from Germany, from Ireland, Finland, Portugal and Jersey who set to influence carers policy first on Scotland’s shores and for that I think you should be incredibly proud. It was especially good though to hear about the experience in Finland and I would echo the words of Marja that we should endeavour to work across our respective countries and learn good practice never believe that a few caring people can’t change the world for that’s all who ever have.
from one another. The Carers Parliament has provided a platform for deep and meaningful engagement meaning your experiences as carers can ensure our policies are right and our national approach is collaborative. Now a country of 5m it is essential that we continue to work together and maintain the strong relationships and dialogues that I think exist between Government, the National Carer Organisations and you as carers. So a big warm welcome to our international delegates and a sincere thank you to all our carers here today for your dedication and for your time. We are united I think by shared commitment to create a Scotland that is fairer, that is equal and treats all our citizens with dignity and respect. That will require all Ministers working across portfolios to make good on that ambition and a point that I know my colleague, Jeane Freeman made earlier today and is also the clear aim driven forward by our First Minister. It’s that broader health policy landscape that I want to talk about.

First if we’re moving onto the enactment of the carers legislation that was passed earlier this year. The First Minister announced our ambitious and positive programme for Government in September with our key aims including, creating a strong, sustainable economy, tackling health inequalities and delivering public services responsive to peoples and communities needs. Delivering this against a challenging fiscal backdrop will not be easy, which is why the challenge the late Campbell Christie wrote of, in his report back in 2011, is still relevant now. We need to not only reform our services to cope with the fiscal climate but also reform services so that they improve the quality of public services, to better meet the needs of the people and the communities they support.

We need to prioritise prevention, reduce duplication and we must empower individuals and communities and in response we are committed to shifting the balance of care away from hospitals and towards primary and community settings. Solutions to the challenges we face as a society can often be found by using and trusting the assets we have in our communities. Moving as Harry Burns described from being passive recipients to active agents of change in our own lives. As the First Minister announced last month, we will be investing a further £500m in primary care by the end of this Parliament. And by the end of the Parliament we will also, for the first time ever, have a path of the health budget spend, not in Acute hospitals but in the Community delivering primary community and social care. This increased investment will support a multi-disciplinary approach to primary care with increased staffing as well as investment in GP services and Health Services where carers and the people that you care for often access services and support. That integration of Health and Social Care is one of the most ambitious programmes of work we are undertaking. Health and Social Care Partnerships are tasked with shifting the balance of care towards a more community based setting, transforming the way we have traditionally delivered services and dramatically, we hope, improving outcomes.

Importantly, carer representatives are on the Integration Joint Board, responsible for the planning of integrated arrangements and service delivery. Carers have the unique perspective to share the design and delivery of our future Health and Social Care Services and it is right that that expertise, that knowledge and that insight is harnessed for the social good of our country. We cannot be complacent and we cannot think either that everything is rosy and I know there is much room for improvement in ensuring effective and also consistent carer input to the work of the IJBs across the country. There is though also good practice to share, I therefore very much support the carers collaborative, the integration work for carers
representatives which brings together all the carers and the IJBs to share experiences and to encourage positive change. The Coalition of Carers has done a fantastic job on making this happen and I’m proud that we can play our part by funding and supporting it.

Another exciting development is realistic medicine that has been developed by our current Chief Medical Officer and is generating International fame. This approach is entirely relevant to carers and to our aspirations of empowering our Nation. Of course the main area of activity of Government directly seeking to improve the lives of carers is the implementation of the Carers Act. Just as the views and the voices of carers shaped and honed the provision within the Bill, so too will your voices be critical to the successful implementation of it in April 2018. Your commitment to improving this Act means it includes the Adult Carers Support Plan, the Young Carers Statement containing information about whether carers have arrangements in place about emergency and future care. Equal Opportunity provisions include having regard to the desirability of Short Breaks being provided on a planned basis, includes carer involvement and hospital discharge of the people that you care for, includes information and advice service having to provide information and advice about bereavement support services for carers following the death of the person that they cared for and it also includes a duty on the Ministers to prepare a Carers Charter.

Your input into the Bill will leave a lasting legacy for carers now and in the future. I thank you sincerely for that effort. Together we now have an opportunity to implement a transformative piece of legislation. The Carers Act will itself strengthen and enhance the rights of carers and contribute towards the improvement of their health and wellbeing, ensuring that they can continue to care if they so wish and to have a life alongside caring. Some of the current figures are 47% of carers living in the most deprived areas of Scotland care for 35 hours a week or more compared to 24% of carers living in the least deprived areas. So we need to make improvements for all carers but to also be aware of the real and significant disadvantage that exists and be prepared to tackle that.

The new Support Plan statement must also capture information about the matters that are important to a carers own health and wellbeing as well as including the practicalities of their caring role. This already happens in some areas but that needs to be consistently felt across the country. An introduction of the Adult Carer Support Plans and Young Carer Statements will also encourage better identification and self-identification of carers enabling better data and a greater ability to implement provisions in the Act to those that need help. To realise the ambitions of the Act we need to implement additional regulations and guidance which does take time but is important to get right. Again this will be a process that echoes the deep engagement that we had with you over the Bill and will also include collaboration with Councils, with Health Boards and Integration Authorities. As well as the production of regulations and guidance, we will also be seeking to support and develop our workforce and raise awareness of the Act amongst carers and also ensure delivery by evaluation.

We need to have comfort that our collective efforts are bringing tangible and positive change and we are setting up a group of key local interests to take forward that agenda. We also, as well want to pilot the Act’s provisions in some Local Authority areas this year and in 2017 before the Act is commenced and are speaking to CoSLA and others about doing this and this will provide ritual earning and help inform the guidance needed for the
Act’s go live date in 2018. Of course we realise there are financial, there are logistical and there are practical challenges for statutory bodies and others who deliver services across Scotland but in pulling our collective resource together and keeping dialogue open I am confident our ambitions in the Act will be realised. Even though the Carers Act has not yet commenced, I want Integration Authorities and all partners to work together and support carers now. This is really important so there is no uncertainty for carers and for my part the changes you need to see in your lives, don’t just rely on that legislation and I’m determined also to ensure we drive forward our existing commitments whether that is ensuring young carers are better supported in schools and looking at innovative short break solutions. It also includes working with my colleagues, including Maureen Watt the Minister for Mental Health to input into her efforts to transform Mental Health provision in Scotland with a strategy to be published soon.

Moreover, as the First Minister touched on, one of our other funded initiatives having a positive impact on communities is Carer Positive and it’s clear that the growing numbers of people who juggle work and caring responsibilities must be supported to return to work or remain in work if that’s what they wish. Carer Positive encourages employers to understand the value of supporting carers in their workplace. It complements our Fairwork and Business pledge agendas, encouraging systems that support the health and wellbeing of employees and building a positive approach to fair work practices and the progress that Carers Scotland has made with the scheme is to be congratulated and the difference it is making determines our commitment to increase the use of Carer Positive by more employers and we are not looking at how best to move forward with that commitment and how it can contribute to the Government’s wider economic strategy. Whether it’s the opportunity of employment, training, the ability to choose a break from caring or to have access to improved joined up Health and Social Care services are all interlinked and they are all equally important.

So to conclude today’s Carers Parliament, previous Carers Parliaments and other initiatives such as the Young Carers Festival really encourage us all to engage to have positive conversations and be involved in participative decision making. While today is often about focussing on the positives we know that we have a lot of work to do to help meet the needs of the daily struggles that so many carers face articulated so well by Cat in her interview.

Often your daily struggles and your daily reality doesn’t often match the aspirations and the policies in the legislation that we have. I also know from my own constituency work that we have a long way to go in meeting our collective desire to see improvement and change. Carer involvement and engagement is now the hallmark of our National approach, you are the experts and our policies and approaches have been benefited by your knowledge and your guidance. There will be times when things are challenging but the strength of our relationship and the openness of our dialog will help move our shared desire to see Scotland a better place to live, to work and to care move a step closer. So thank you once again for your time and thank you for your contributions and for participating today and I look forward to taking your questions and again thank Carers Scotland for their time in creating these dynamic and influential platforms for debate and discussion so thank you and I look forward to working with you as we take forward the work that we all want to see happen across Scotland.

Thank you.
Ruth Wishart
Thank you very much Minister. You will have noticed that we have had messages from three Ministers today including the First Minister and they have all been female, I like that in a Government. Now we have some questions to the Minister here and for speed as much as anything else I am going to ask that they have come from specific people.

The first one is from Geoff Kitchener:

How can the Carers Scotland Act and the integration of Health and Social Care improve support for carers like him who are juggling almost full time work with more than 35 hours of caring every week?

Aileen Campbell MSP
That is a point that was also made by Cat, I think, in the interview as well and I think it’s an issue that we still need to grapple with. We are committed to supporting carers whether or not they are in employment so I think that’s why moving forward the Carer Positive work is a big important step. I think from influence from my previous portfolio which was children and young people, I think there is a similar dynamic with the work that we did around early learning and childcare as well because I had to try and meet the needs of people to be a bit more flexible and probably there is a similar amount of work that we can learn from that echoes that desire to see things happen to make life and work fit that wee bit better. I think there is probably a bit more work we can do across the portfolio alongside other Ministers as well. Certainly the work that we are doing around Carer Positive, the desire that there has been from other employers to get involved, the work that we see happening already is one way to try and move that forward and to just articulate a bit more cleverly the benefit employers can get from the knowledge and the experiences that you have as carers as well and to be a bit more flexible in the approach. Legislatively I think you can request employers to be flexible. To request flexible working and I think possibly we need to work and to coordinate the efforts that you have in different areas of policy a bit better so that can be realised more by the experiences you have as carers.

RW I think he was hoping that the Carers Act would actually specifically facilitate some of these ambitions.

AC I think absolutely, it also means that we can create a dialogue and continue to work with the Carers Organisations, work with employers, raise awareness and keep these conversations going as well.
RW I’ve got a second question here which is from Margaret Graham McDonald and she asks:

Q2 How can investment be made in a range of short breaks that meet the needs of different families and carers? This is a huge question, I think you know, a question of respite not just getting it but getting it at the right time.

AC Absolutely, I think as well there’s to be a bit more imagination about this and I think the old fashioned static models are not necessarily what everyone wants and I think we’ve put investment into short breaks, we want to ensure that these are given to families and provided for families at the appropriate times so that they can properly benefit from the respite that’s on offer and also why we’re developing the hospitality work as well. So we have invested in a number of areas to try and improve the respite that’s on offer but again I know we’ve got a long way to go. It took her three years to get respite. She got 4 hours a fortnight and that’s not going to meet the needs of her wee boy that she’s caring for, it’s not going to meet the needs of the siblings who often feel that possibly attention is not with them either as well so I think that’s why the Act is so important as well because we are trying to make sure people take a holistic view on people’s family lives as well and that has to then work hand in hand with the development and investment we have put into the respite services.

RW The next question is from Fiona Thomson:

Q3 Some of us have had poor experiences when the people we care for are admitted to hospital and planning for when they are ready to come home. How will the Carers Act make a difference and we’ve heard a fair bit today about bed blocking, it’s really about lack of facility in the community and lack of resource in the community?

AC Again as my predecessor, Jamie Hepburn took the Bill through the Parliament. I think it is one of the areas that carers had a direct influence and had highlighted this was an area they wanted to have more influence in and is within the Act as well and that there would be an opportunity for carers to make sure they are involved in that discharge. There is a reality there as well and hopefully will be eased with the integration with Health and Social Care about the matching up of resources and the matching up of what’s available in a local setting.

RW Next question comes from Catherine Bingham who I can see lurking over there. Catherine has said not all carers know what their rights are when dealing with Councils, social workers, GPs and other services. A Carers Charter is mentioned in the Carers Act and in fact you mentioned it yourself. [Catherine’s question is:]

Q4 Will the Carers Charter be in place at the same time the Act is commenced?

AC I think we need to work on that sequencing because what I also mentioned was the regulations and the guidance, certainly there was a commitment to work on the Carers Charter and we need to work together on that to make sure when we can bring that forward that it meets the expectations that you think you have. Certainly, I know there has been some concern about that because it had been there and then the Bill came along so we need to work, I think, to get this moving and to make sure it can sequence as well with the regulations and the guidance.

I think we need to plan that in the right sense because the regulation and guidance to come forward but certainly the commitment is in the Act to have the Carers Charter so we will work with you on that.
Q5 How do you plan to increase the availability of respite care to people with dementia in their family which is particularly challenging for a lot of people?

AC Yes and I think probably Cat’s situation is probably something that we are going to have to be mindful of as well and the people who have dual caring roles, elderly parents as well and that’s something that we can probably share experiences with from the other countries that are here today as well. It’s not just a Scottish issue we are dealing with around our ageing population that’s something the Western World is dealing with as well so we do need to ensure the right support is there and that’s why the support statements, the plans that carers should expect from legislation should be better to holistically take note of.

RW I think that the key word in that question is availability. So I think nobody would doubt the intention of the ambition of the legislation, it’s having the resources on the ground.

AC Absolutely and again that’s why I think taking note of the whole circumstance of a family is important to ensure that people are clear about what a family needs to cope and survive and to thrive as well and we need to make sure that the resource is there. We need to make sure that the ability to deliver on what we’ve put out on the legislation can be realised.

RW We have a final question from Lyn Northrop and she’s asking:

Q6 It appears there’s been a lot of attention to what support can be given to carers who give up employment to look after a loved one. However, what support can we give those who have little respite and juggle full time employment and their caring responsibilities?

AC Yes I suppose it will be a similar kind of answer around the work that we need to do around the Carer Positive making sure that employers can recognise the benefits and the value that they gain to be a much more flexible employer. I know that there are some great examples out there where employers are doing that for a variety of reasons whether it’s young children or elderly parents or for whatever reason and just that little bit of flexibility that I think Cat spoke about, about being able to come in a wee bit later or come away a wee bit earlier. Being recognised that the pressures that families are under, the carer is under, making sure that we can get employees to recognise the benefit they can have by being more flexible, it’s important. Of course there’s an economic benefit to having people in employment and working and contributing to society as well and perhaps the story that we tell around that needs to be more strongly articulated to show and illustrate to employers that there is a pool of talent in amongst our carer population that we should use and utilise.

RW You said in your speech Minister about the journey that’s been made by the Carers Parliament and the Scottish Government working together to try and get the legislation to improve their life chances and experiences. If you were to have one sort of last message to the Parliament that you hope will happen by the time the legislation is in force, what would that be?

AC Well I think undoubtedly the Carers legislation was improved by the engagement that Government had with carers and their experiences are real lived experiences. The stories that you tell away from the stats away from some of the more formal ways of communicating. I think the experiences that people had has definitely had a lasting impact on the legislation. I would hope that, being mindful of the experience that you’ve all had, the fact that that has shaped the legislation was moved forward and that when that comes to life it does have a demonstrable impact. And, because of your impact on people’s lives, that you have that dignity and the respect that you need, the ability to have holistic care and support that you need in order to function, to thrive and survive in your communities. I hope that that is realised but I hope it doesn’t just take the legislation to kick start that, it needs to start earlier. We need to work together about what we can do now and to improve things before the legislation goes live. I think there’s lots of good practice out there, I think we can learn from where that good practice is and hopefully we’ll be in a position where we’ve got a consistent approach about how we treat and respect carers in the country. Things have moved on an awful lot and I know from my own mother’s experience the way in which she relied on Crossroads when she was caring for her elderly father that that little bit of support, that bit of kindness, that bit of community support as well was so important. So I just think we need to build on that and use the legislation as a platform for us to not just see that we resting on our laurels, being complacent thinking that’s the job done, being vigilant and making sure that things can continue to improve.

RW Thank you very much. Join me now in thanking Aileen Campbell MSP.
FINAL THOUGHTS
& CLOSE

with RUTH WISHART and GRAEME REEKIE:

Ruth Wishart
During the period over lunch and before and after lunch you had an opportunity to share your own experiences in the workshops but you also had what I thought was a really imaginative set of opportunities out there to discuss your own visions and aspirations for a better Scotland and we had as you know the Wishing Wall, the Model Village, all manner of things where you were able to contribute your own thoughts and ideas. I’m going to ask Graeme Reekie to come up and join me now because he’s paid assiduous attention to all the things you’ve written down and we’ll just try and quickly sum up some of the things that we’ve learned from the day. I think we should start Graeme by asking are there any consistent themes that came out from peoples aspirations and visions?

Graeme Reekie
We’ve been hearing about them today some of the things about employment and about clarity of benefits and with paid workers and what I was going to attempt to do because there is a whole lot of information that people have given us.

I can sum up some sort of 5 big statements that people have given that certainly stick in my mind and hopefully will be useful for your memories as well.

“We’re not an employed or jobless carer.” These are your words not mine.

“No more fear of brown envelopes relating to the story we heard this morning”. We know what that’s about.

Being a young adult is stressful enough; it affects our own mental health. There should be special short breaks for young adult carers.

There was also a bit of a message about:
“can we start talking about young adult carers.”

Thank you, if you like those so far, we are going to get on great.

I quite like this one (and I don’t think that you will disagree):
“A social worker’s job is outcomes not budgets.”

Ruth Wishart
Ladies and Gentlemen by some miracle I appear to be finishing on time and given this morning that is really something of a miracle.

Thank you all enormously for the contributions you’ve made all day today because a myriad ideas have come out of today which thanks to Graeme and his colleagues will be able to have access to later on.

All it remains for me to do is to thank all the organisers, thank the Scottish Government, thank Carers Scotland, thank everybody who contributed to today and wish you all a safe journey home. Thank you very much.
EVALUATION & CARER PROFILES
EVALUATION

We asked those who attended the day to rate their experience and their views on speakers, workshops and activities.

THE MORNING SESSION

Three speakers took part in the morning session which included a Q&A session to the speakers facilitated by Chair, Ruth Wishart.

85% rated Minister for Social Security Jeane Freeman MSP’s contribution as good or excellent

50% rated Councillor Peter Johnston’s contribution as good or excellent

96% rated the contribution of carer Lynn Williams as good or excellent

“Jeane’s contribution not only felt heartfelt, she came across as wanting to make things better and was not just toeing a party line.”

“This speaker answered a lot of questions for me, very clearly and succinctly. She also clarified why and where and some of the challenges might lie. For example, she explained some of the potential challenges around some issues being devolved to the Scottish parliament while others remained reserved to Westminster.”

“Again very positive about the future for carers.”

“I understand that there is a passion and desire for services to people experiencing difficulties to improve but there is no clarity about how this is going to happen when front line services are being decimated.”

“Excellent and brave contribution by Lynn Williams.”

“This was a very powerful session from a lady who is also very articulate & eloquent, especially about her situation. My only advice would be to stop apologising when upset! She has every right to feel and be upset by her dreadful experiences and situation and if more people were able to express their emotions more freely, especially in such circumstances, perhaps more notice would be taken by those who need to listen.”
THEMED DISCUSSIONS

RATINGS
A number of workshops were held on the day and we asked participants to rate their discussion session. Their responses are shown in the pie chart opposite.

DURATION
50/50
Participants were split almost equally 50/50 that time for workshops was “about right” or “too short”.

SHARING EXPERIENCE SESSION

This was followed by a Sharing Experience session, a summary of which is included earlier in this report.

86%
rated the shared experience session as good or excellent

“By far the best bit of the day. Particularly liked the carers village and the way you could contribute by writing stories, anecdotes or ideas on any part of it. The sharing walls were also good”

OVERALL: THE MORNING SESSION

86%
rated the overall morning sessions as either good or excellent

VENUE & CATERING

87%
rated the venue as good or excellent

82%
rated the catering as good or excellent
THE AFTERNOON SESSION

Two speakers took part in the afternoon session. Carer, Catriona McRoberts, took part in an interview via Skype and Aileen Campbell MSP presented live to the audience.

90% rated carer Catriona McRoberts' contribution as good or excellent

38% rated Aileen Campbell, Minister for Health & Sport's contribution as good or excellent

“Heartbreaking stories, but I can guarantee they were stories that every carer in the hall recognised.”

“I kept thinking throughout the interview – what unimaginable courage carers show every day. I say we are the “glue holding Scotland together.” We allow so many people the time and space to live their own lives.”

“Outlined the tough job ahead but very positive”

“Although she spoke well, I was not left confident that things would change”

OVERALL: THE AFTERNOON SESSION

71% rated the overall afternoon sessions as either good or excellent

THE CHAIR

96% rated the Chair, Ruth Wishart as good or excellent

“Ruth is an excellent chair, clear confident voice. She manages to hold the smooth running of the meeting.”
PROFILE OF ATTENDEES

180 carers attended the Carers Parliament. We asked participants to tell us a little bit about about themselves and their caring role.

**GENDER**

- **79%** female
- **21%** male

**ETHNICITY**

- White
- Pakistani/Indian
- Mixed ethnicity
- Black/Caribbean

The majority who attended were White Scottish, Irish, English or British, 2% were of mixed ethnicity, 2% Black/Caribbean and 6% Pakistani or Indian.

**AGE**

- 17 or younger: 4.46%
- 18-20: 0.64%
- 21-29: 5.10%
- 30-39: 7.64%
- 40-49: 31.85%
- 50-59: 22.29%
- 60-69: 20.38%
- 70-79: 5.10%
- 80 or older: 2.55%

**DISABILITY**

- 31% of delegates said that they had a disability or long term condition.

**SEXUALITY**

- 6% of delegates identified as LGBT. The majority who attended were heterosexual.

Note: with some carers undertaking dual or multiple caring roles, not all figures will add to 100%.
CARING ROLE

We asked delegates a range of questions about their caring role including numbers of people they care for and the disability or illness of the person they care for.

The following charts provide details of their responses.

How many people are you providing unpaid care for?

- 1 person: 71%
- 2 people: 19%
- 3+ people: 3%

How long have you provided care?

- 0–4 years: 6%
- 5–9 years: 32%
- 10–14 years: 15%
- 15–19 years: 12%
- 20+ years: 25%
- Other (please specify): 11%

Other involvement

Of those who attended, many were also involved in things such as carers centres, integrated joint boards and local voluntary organisations:

- Health and social care partnership: 20%
- Local carers strategy group: 23%
- Local NHS public involvement forum: 7%
- Local carers forum: 32%
- Carers centre board: 14%
- Voluntary organisation board: 28%
- On another group: 44%
Who do you care for?
Tick all that apply

- Child over 18: 25%
- Parent or parent in law: 43%
- Child under 18: 15%
- Spouse or partner: 21%
- Sibling: 8%
- Another relative: 7%
- Friend or neighbour: 3%

What condition do they have?
Tick all that apply

- Long term condition: 50%
- Physical disability: 49%
- Learning disability: 27%
- Mental illness: 25%
- Frail because of old age: 25%
- Dementia: 22%
- Drug or alcohol dependency: 3%
APPENDIX 1

Individual Workshop – notes in full

SOCIAL CARE WORKSHOP
HEATHER FISKIN

Make different political choices – APD Vs better social care – what do we value?

Social work should receive more funds to support carers at home. The hours of support for the most disabled have been cut substantially in the last few years. Carers are at breaking point.

To carers – find your voice – ask, ask, ask again. To Scottish Govt: be careful we carers do not form a union! Join carers on Facebook.

Delayed discharge: It is not illegal to leave a hospital without a discharge letter – they will post it to you. But how do we get them to hurry in a pharmacy?

If you are the one and only carer for someone, you need to know you can contact someone if you have an accident or become ill. What is in place in Scotland in the 21st century?

How do we find out what social workers do? Are they the first contact in the care system?

Council social work departments – should have a person on their staff who is completely independent of the local authority but who has knowledge of the services’ systems which need to be negotiated when someone is a carer. If someone is unsure of how to access benefits, social care, care establishments, they could ask for this without the need for rules.

Palliative carer options so you can be together to the end.

Local council – why can’t respite money that councils provide be used by carer to have respite break?

PARENT CARERS WORKSHOP
SUSAN WALLS

Transitions from children’s to adult’s services or onto older peoples services should be led by circumstances, needs and abilities, and not simply defined by age. Age alone doesn’t mean much. Transitions need to be far better planned and particularly in school and education settings, started a lot earlier to give everyone time to adjust and get the best from new experiences and ways of life.

At what age do you stop being a parent carer? (First event I’ve attended and not had the ‘label’). You never stop whatever you are carer for your child/adult child.

Providing access to ‘carers groups’ suits some but is not the answer for all carers.

Carers looking after individuals with complex needs requiring 24 hour care need more support other than from third sector, as many carers do not have the time or energy to find support groups or look for carer organisations.

Parent carers are often looking after other children and not just the child with additional needs/disability. Any support provided needs to take that into consideration.

I speak to many carers with young children with disabilities and they are incredibly frightened for what the future holds. Lack of help, lack of support, no straightforward way to access information. Many have lost their own identity and don’t know how to be a ‘person’ again.

MENTAL HEALTH WORKSHOP
KAREN MARTIN

Carers looking after profoundly disabled individuals need very quick (fast track) access to mental health services. Too many carers now on anti-depressants due to caring role.

New partnership (genuine) between professionals and carer. This may happen with physical condition but is not happening when cared for has mental health issue.

Mental health support for siblings of ‘disabled’ child.

Abolish sectioning and compulsory treatment under the Mental Health Act (except where a crime has been/will be committed). People with a mental disorder should have the same rights to refuse treatment as those without.

Carers mental health suffers due to an uncaring system. The stress of the ‘brown envelope’. Not knowing if arbitrarily been called in for re-assessment and if financially this will break you.

Confidentiality – staff can speak to carers and carers can speak to staff and give valuable information. This is not breaching confidentiality.

Need professionals to understand the impact of ongoing challenge of caring for person with mental health issues on the mental health of carer. Saying ‘you must be feeling much better/happier’ to a carer when the cared for person is in less intense distress is not helpful.
EMPLOYMENT WORKSHOP
SUE MCLINTOCK

You shouldn’t feel you are being punished for wanting to keep working and being forced to give up work due to paying for care.

We should learn from ‘carers leave’ in Ireland – time off for caring responsibilities with your job being held for you to return to – similar to maternity leave (with financial support to do so).

When an employer supports a carer long term, it is reciprocated by the loyal employee willing to ‘go the extra mile’ to repay the trust shown in them!

Employers should recognise the fluctuation in the caring role, ‘for better or worse.’

Will carers have replacement care hours provided in order to allow them to access education or employment?

Employers need to realise that valuing carer employees will boost productivity and morale. Government need to instil this mentality for the good of everyone.

Look at Scottish Business Pledge – push flexible working practices – benefits of this.

EDUCATION AND LIFELONG LEARNING WORKSHOP
LOUISE MORGAN AND PAUL TRAYNOR

Health, social care and education need to make ‘working together’ a fact rather than fiction. One person contact for carer would be ideal.

Provision of recreational classes/workshops seems to vary from one local authority to another. A more coordinated countrywide approach would be beneficial.

In my experience when the local authority were looking to offer (education) it was to support my caring role, but what about my lifelong learning? Part time courses for modern day life skills.


School not knowing why attendances is so low. Not getting a chance to explain why. Homework struggles and getting distracted in class due to worrying about the one you care for.

Someone needs to take responsibility for additional support for learning. Allowing local authorities to destroy the system and make a mockery of GIRFEC cannot continue. A generation of young people being failed. Third world education in a first world country. Disgraceful.

Look at how carers can be supported (i.e. lower grades) to get placements in educational establishments i.e. if they are carers they get an interview and caring impact is taken into account.

Schools need to listen and involve parents more in decision making. Carers of profoundly disabled children should be advised of transition planning in written form and it should be made clear when this should start.

Exams – it is not clear what level of exam support will be put in place for disabled until exams are right on top of you. Support arrangements should be put in place at start of curriculum, not just when exam arrives.

Feel valued.

DISABILITY BENEFITS WORKSHOP
LIZ DAVIDSON

Application forms need to better reflect the specific issues re mental health conditions

The current social security system should be scrapped replaced by an entirely new one.

What is the purpose of the system? Is it to help people gain support or to prevent them claiming? If it is to ‘help’ then forms, procedures need to be reflect this. Current system feels like it’s designed to prevent successful application for social security.

Assessments – First off, do we even need face to face? If we do, it has to be public bodies not private enterprise. The people’s role should be to ‘enable’ successful claims, not to prevent.

Helpline staff need an understanding of how a condition affects people and how some people claiming benefits are made to feel. Staff must be allowed to deviate from a pre-written script and have an actual conversation with callers.

Plain language – stop the obfuscating. Tell people what their award is in simple easy to follow language.

The DLA forms are long and difficult to fill in. All it looks at are all the negative aspects – completing it for my child is distressing. Why do I have to go through this again for PIP?! His condition is lifelong.

Young carers shouldn’t have to worry about finances. Or the person to care for’s benefits being taken away.

Need a single point to call about all benefits. They then direct you to correct department or help that you need.

Assessments shouldn’t be made of health. Workers who know about the disability the person has i.e. mental or physical health.

‘People skills’ training for all benefits staff. (Ours was fab by the way but other friends suffered).

Language – it is not a ‘benefit’ to be disabled so never call our payment system a benefits system. We must always refer to it as ‘social security’ to break the stigma.

The unfairness of the rules on benefits assessments. Carers do the person’s hair/make up/dress them – proper flexible packages – I put my mum’s make-up on and they assume she did it and say she’s fitter than she is.

When one benefit is for life it should mean that.

All too complex, needs to be simplified.

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When one benefit is for life it should mean that.

All too complex, needs to be simplified.
HEALTH AND WELLBEING WORKSHOP
DON WILLIAMSON

Universal services to support the health and wellbeing of carers.

Single point of contact in health services – a ‘carer aware’ person.

Better support for carers in this area – access to support/programmes to maintain positive health and wellbeing and easy to access interventions when health and wellbeing deteriorates.

CARERS BENEFITS WORKSHOP
DAWN ABELL

In education you get a bursary not a wage. It should not bar you from receiving Carers Allowance.

Carers Allowance could be used to fund micro renewables for recipient’s home and thus lift them out of fuel poverty.

Carers Allowance should be paid on an hourly rate to all carers young and old, no matter what their age.

Young carers payment/bursary to help those young people in households with low incomes.

Free transport for carers, especially in rural areas, to access services and leisure opportunities.

Carers Allowance stops when I’m 65. Pension starts when I’m 67. How about some fairness? I’m also a WASP woman!

£8.25 an hour for carers – all carers. We need a living wage! No more rhetoric about Carers Allowance now being equal to Jobseekers – disgusting!

Pensioner carers: We have worked all of our lives to pay for our old age pensions. We are still doing a job, many of us 24/7. No job description, no holidays, no tea breaks, NO CARERS ALLOWANCE. Who in their right mind would apply for this?

Increase Carers Allowance earnings disregard.

Retired Carer is still caring under difficult circumstances because she is older. Just because she receives pension – she does not stop to be a carer. No Carers Allowance for pensioners!

Earnings limit: Why? It make no sense it being there, especially as so many ‘may’ be able to do some work from home between caring duties.

We need pensions! No job – state pension delayed to 67. Not fair!!

When you reach pension age Carers Allowance should not stop. I am still a carer. I would sooner go out to do a job of work and receive a wage rather than claim benefits.

Charges for carers being waived is great! Charge for the people they care for not so great.

Carers should get a living wage not a scrappy allowance.

Peter Johnstone spoke about Scottish Living Wage being £8.25. Will this be reflected in people’s Direct Payments to enable PA employers to pay Living Wage without having to reduce hours provided in existing care package?

Carers providing 24/7 personal care and due to the level of care required have to be in the same home should receive a higher/enhanced Carers Allowance.

Support with leaving home when you have had a full time caring role.

A FAIRER SCOTLAND FOR CARERS:
CARERS (SCOTLAND) ACT 2016
CLAIRE CAIRNS

With all due respect, 2018-2020 does nothing for the carers today.

Carers Support Plan should unlock carers’ budget in SDS, but not to reduce the cared for’s budget.

Do not agree with carers having budgets taken away from person they care for. How will these be monitored?

Emergency plan needs to carry weight with statutory services.

Need a national framework for adult carer support plan – but local questions or discussions should be able to be added – a degree of flexibility.

Hospital discharge planning should start on admission and must involve carer from outset.
BUILT ENVIRONMENT AND ACCESSIBILITY

2. Green spaces for mind, body and soul.
3. Access to public parks needs to give access to all. If a wheelchair user can access it, so can pretty much everyone, but currently too many barriers.
4. Park benches need to be fully accessible. Designed by someone who understands various disabilities, not only wheelchair.
5. Disabled friendly gardens.
6. More disabled friendly access.
7. Lifts and ramps in buildings.
8. Better design of streets to make them accessible to all. Lighting, drop kerbs, contrast between road and pavement, grab rails.
9. Why have lift access then say wheelchair uses can’t use upper floors in case they become trapped in the event of a fire?
10. Make all buildings accessible.
11. Proper dropped kerbs – flat! With separate wheelchair access outwith visually impaired ‘knobbly bits’.
13. Free accessible public toilets
15. PAMIS toilets – fully accessible adult changing
16. Welcoming, accessible buildings!
17. No dementia ‘hubs’ in high rises, too isolating.
18. Zebra crossings instead of traffic lights.
19. Part time traffic lights.
20. Accessible rooms in hotels should be more than just getting into the room
22. Dog friendly.

ACCESS TO TRANSPORT

1. www.change.org – free concessionary transport for unpaid carers and sign the petition!
2. Carers, especially those in receipt of Carers Allowance, should get free transport
3. Free travel for young carers.
4. Free travel.
5. Free travel.
6. Carers should receive support for transport and access to services.
7. Free transport for carers to enable them to use services – especially in rural areas where costs are steeper and services fewer.
8. All carers should receive a discount or concession on public transport to enable the carer to do some of their caring duties easier and quicker.
10. Carers need concessionary fares on transport in their own right.
11. Integrated transport to include wheelchair users and covering all rural areas.
12. Demand responsive public transport as used in rural areas e.g. Perth & Kinross Council DRT taxi scheme.
13. Accessible community transport, suitable for all disabilities.
15. Bus drivers should learn not to question you when buying tickets – learn this can be upsetting for dyslexic people.
16. More inclusive cycling, like Glasgow’s Freewheel service.
17. Lollipop people who smile and say hello!
18. Car drivers being aware that wheelchairs need space – not having to get round cars parked on pavements.

APPROPRIATE SERVICES FOR CARER & CARED FOR

1. Social work to work on outcomes not budget. (Comment: ‘Agreed’)
3. Support in home not at expense of traditional services.
4. Health and wellbeing hub for all community, on a high street or central location.
5. Keep libraries etc. open as carer and ‘caree’ hub.
6. How can we set up a carers get-together within the community?
7. Specialised care centres with enough funding.
8. More support for young/all carers caring for someone with dementia!
9. Support for carers who are pension age and younger carers.
10. Avoid ‘special’ services. Let’s all socialise together. Make accessible for all.
11. Look at the Rudolf Steiner/Camphill village for the way to treat adults with special needs.
12. More facilities for cared for at weekends and after 5pm.
13. Carers need real support not snappy sound bites!
14. More services that are friendly and trained to deal with young people with dementia, not just over 65s!
EDUCATION
1. Schools consider having a young carer class as part of the curriculum example – Wallace High School.
2. Trustworthy people for young carers to talk to.
3. Proper training for all teachers, educators and decision makers.
4. OU getting behind carers commitment to Higher Education.
5. Recognise young carers need support in education. Consider action for carers grades.
6. Using my YC (Young Carers?) authorisation card in school to get support.
8. Telling lecturer/teacher I am a carer and getting ‘special treatment.’
9. Education of staff re: health/welfare – not just care staff also shop staff, toilet attendants etc.
10. Accessible education for all children in Scotland.
11. All school staff should receive training on carers.

EMPLOYMENT
1. Realistic support for cared for to get into and stay in employment if the individual has that capacity.
2. More advice and help for ex-carers making the transition back to employment.
3. Young adults with ASD are not unemployable – some just need support on ongoing basis in the workplace.
5. Proper support from work when emergency arises.
6. Employer to allow time off work so you can go to appointments with the person you care for and not have to use holidays or unpaid leave.
7. My boss would understand a sick mum in hospital with dementia is the priority for a sole carer.
8. Flexibility from employers on what caring entails – more flexi-time.
10. Fully accessible.

FUNDING
1. Stop spending money on tick box exercises and start funding services instead.
2. Outcomes to be met, not budget.
3. Funding for young carers.
4. Funding should be made available for young adult carers.
5. Increased carer support, not decreasing it!
6. Care should be free for all.
7. Disabled people who need 2:1 get a budget x2, not halved.
8. Free personal care for all not just for over 65s.
9. Stop closing services. SDS is purely used for cost cutting.

INCLUSION
1. Not all families stay in touch or talk!
2. Carers to access medical records for the person they care for.
3. Even though I was my mum’s full time carer and coped reasonably well with her dementia, I was deemed too young and immature to be her power of attorney. My older sister was next of kin as she is the oldest, however social work became her power of attorney and guardian as my sister was unfit! When my mum went into full time care at a hospital I was not made aware of any decisions or meetings – only my sister as next of kin – disgrace. Not all families stay in touch so I was not made aware when she took ill, as it was deemed my sister’s responsibility – not good.
4. Include family and friends who help to care and offer payment through SDS.
5. Treating carers as equal partners in care.
6. Look at bigger family picture as often everyone is caring.
7. Carer should be made aware of any decisions made, not just ‘next of kin’.
8. Debenhams (name and shame) – corporate sexism. Refuse to allow male carers into changing room to help female partner try on clothes. Disabled people should have the dignity to try on clothes without being forced to rely on a stranger. Have a stranger imposed on them, even though their carer is present.
9. People who can’t attend these events because of caring role would have some arrangement made for them to come.

RESPECT AND UNDERSTANDING
1. Pharmacies should respect young people picking up prescriptions for the people they care for.
2. In multi storey buildings) giving lift priority to wheelchairs and pushchairs.
3. More understanding from agencies.
4. Better understanding of complex needs.
5. Respect me as a carer – I live my principles.
6. Everyone, no matter the profession, would have training to deal with additional needs (physical and mental) therefore as a carer we would run into fewer ‘judges’.
7. Education, nurses, doctors, social work, teachers – walk in my shoes.
8. Seeing people not just statistics or as a case.
9. Some better service in businesses i.e. old fashioned customer care – not ‘dementia friendly’ or ‘autism friendly’, just friendly.

SUPPORT FROM COMMUNITIES
1. Carer friendly communities need carer buddies as back up.
2. Neighbours being friendly and accepting my son and his illness.
3. Neighbourhood Watch-type communities – local volunteers who can lend a hand every now and then.
4. People would smile at me and say hello!
5. It is as simple as being made to feel welcome! Smile
6. Disabled bay outside our house – but community need to understand we need it!
7. You could go to a public space e.g. a café and go to the toilet and someone would watch your cared for person for 5 mins.
8. Look to Newton Dee village for the model community.
9. It should be a community where time is set aside for the person being cared for, that they are not rushed and become confused. Also always treat them with dignity/ respect.

QUALITY CARE
1. Carers and those being cared for want normal life in community. Care in home is not what it should be.
2. More care home staff per resident.
3. Make sure that employers (i.e. councils) observe the European Working Time Directive for care workers.
4. Reliable carers from NHS services e.g. always the same people.
5. Staff who come to people’s homes to do simple activities.
6. Follow examples of good practice – carers employed by Scottish Borders Council – by support worker employee and full time carer.
7. We need reliable friendly on time, constant care from social services.
8. Reliable committed staff.

FINANCE AND CARERS ALLOWANCE
1. Pay paid carers a higher wage.
2. Stop the care tax.
3. Caring must be valued as work!
4. Carers Allowance for pensioner carers – we worked for our pensions like everyone else but still do a full time job.
5. Should be able to work and reap the benefits like everyone else.
6. Better payments so I can take my husband out (wheelchair).
7. Education is a right and so is Carers Allowance! Should get both.
8. Carers allowance should not stop when carer comes to retire as caring role does not stop, in fact it gets harder. Old age pension is not a benefit, it’s paid for!

HOUSING
1. More housing with disabled access.
2. Affordable housing for carers.
3. Homeless services shouldn’t have to ask the person who made you homeless if this is true. I was made homeless due to my dad’s mental health condition! He can’t understand why I was homeless!
4. Paying a mortgage on Carers Allowance is difficult. More affordable housing required.
5. To make more housing for people with learning disabilities.

PSYCHOLOGICAL ACCESSIBILITY
1. Not everyone can deal with community, so more options should be available.
2. ‘Quiet’ shopping times for ASD!
3. Better access to services such as benefits, respite, funding, social work and recognition of what we do.

4. Single point of contact (telephone or web) – direct you to all services – help groups, 1-1 work in your area. Most still word of mouth of who can help and what’s available in your area.

5. Quiet areas for carer and cared for person.

CARERS’ WELLBEING

1. Self-care
2. Peace of mind
3. Joy
4. Fun, dance, sing!
5. My health matters! My mum would hate to think my love for her made me ill and lost job.

RESPITE/Breaks

1. Respite/day support centre community hub in evening.
2. We need respite breaks for young adult carers.
3. Know what respite I am entitled to.
4. All carers need respite. Not just looked at as short breaks for the cared for.
5. As an employee I am entitled to 5-6 weeks paid leave. As a carer please consider at least 5-6 weeks respite.

YOUNG CARERS

1. Local councils should help to fund young adult carer services.
2. More support for young carers.
3. Funding for young carers (not just 16+)

BENEFITS

1. Assessments that work with the disabled people, not against them
2. Carers tax credits
3. Be given the benefit of the doubt (PIP)

OTHER

1. What helps the cared for – help the carer!
2. Safe!
3. Post care psychological support for carers.
APPENDIX 3
Wishing Wall – notes in full

EDUCATION SUPPORT
1. Support for going into further education while balancing a caring role.
2. EMA top up for Young Carers.
3. Bursary instead of student loan if you're a student.
4. More support for student carers.
5. Top up bursary for student carers.
6. Student carers should automatically receive a bursary as often parents income is spent on caring, no matter to what level. Carers Allowance too.
7. Mandatory training for teachers and lecturers and employers on carers.
8. A chance to get into uni with lower grades if we do well and we are on track.
9. Teacher training so that we don’t get in trouble for things out of our control.
10. An appropriate education for all children in Scotland, regardless of level of need (instead of 7 years of fighting and still no education).

QUALITY CARE
1. Better care in the home provided by the council.
2. Sort out crap care – make it unacceptable and illegal.
3. I wish professional carers earned more/got expenses etc. when they come to the house to care. It’s sometimes very depressing, they can look very stressed and harassed.
4. Services will continue at a reasonable level.
5. More support for cared for that are young with dementia - not all are lost
6. Good outcome for cared for person is what makes biggest positive impact on carer.
7. My daughter was well looked after with stimulating activities in place, and cared for as well as possible in the community and provide passionate care so I could die in peace.
8. Make sure that the council observes the European Working Time Directive for care workers.

EMPLOYMENT SUPPORT
1. Long term support to enable cared for to gain and retain employment. Short term support not sufficient if condition is long term, e.g. mental health, autism.
2. Support to allow all carers to work.
3. Stop employed carers losing their jobs. I lost mine, not fair!
5. Mandatory training for teachers and lecturers and employers on carers.
6. More support for working carers getting back to work.
7. All H&SCP's and councils and TSIs and care providers to be Carer Positive

SYSTEM CHANGE
1. Root and branch change that deals with the basic issues.
2. End the postcode lottery.
3. Make the system suit carers and cared for rather than those people trying to fit in the system.
4. Be a more caring society.
5. Reintroduction of true welfare state through ‘tax and spend’
6. Care charges should be standardised.

CARERS ALLOWANCE
1. Carers Allowance for working carers.
2. Fairer rate of Carers Allowance.
3. Carers Allowance for older carers.
4. A carer is not my identity, it is part of my life. Carers Allowance doesn’t recognise or reflect this!
5. Carers Allowance to be equal to Living Wage - we are not unemployed, our job is caring.
6. Carers Allowance for working carers.

FUNDING
1. Young adult carers need funding!
2. Support to meet outcomes and not to be a financial cost.
3. Funding for Young Adult Carers.
4. Better funding for support groups.
5. Stop patronising carers, we don’t need a pat on the head and told we are appreciated, we need funding and services put in place. Care Act is a waste of the paper it is written on without money to back it up.
6. Young adult carers need dedicated and reliable funding.

MORE AWARENESS OF CARERS ISSUES
1. Social work staff to be more aware of situations!
2. Housing and homeless support services who understand and recognise the difficulties of caring for someone with mental health.
3. Agencies to listen.
4. Better understanding of complex needs and 2-1 care, not half budget due to needing more support.
5. More awareness.
INCOME
1. Universal basic income for all.
3. A pension I can live on and not in poverty because of caring role. Prevents me adding to my work pension.
4. Recognise and pay carers as the workers they are, not the claimants that the government makes them out to be.
5. More money for carers commensurate with the job they actually do, and save the NHS and social care budgets.

CONCESSIONARY TRANSPORT
1. Free transport for carer.
2. Free concessionary travel/help with transport so it’s affordable.
3. Free travel for carers.
4. Fee/resourced travel, Scotland-wide for carers.
5. I wish for free/concessionary public transport for carers of all ages.

SUPPORT FOR YOUNG ADULT CARERS
1. More support for young carers and young adult carers caring for a dementia sufferer.
2. Bereavement support for young carers and young adult carers.
3. Help from youth organisations to identify young and young adult carers.
4. Recognition of young adult carers, not as a young carer, not as an adult carer.
5. Listen to young adult carers need for local services.

RESPITE AND BREAKS
1. More support with respite care and breaks.
2. Respite.
3. Easy access to breaks for carers.
4. Specific short breaks for young adult carers as young adulthood is already trying enough on your mental health without being isolated because of your caring role.
5. More respite for older carers.

INVOLVEMENT
1. Genuine partnership between professionals and carers. Carers know the cared for person they are expected to pick up the pieces when the system fails. Carers should be involved even if confidentiality is an issue, professionals can still listen to carers and hear what they are saying.
2. Carer to be involved in decisions not just cared for’s next of kin.
3. Better support through partnership working for LGBT carers, not every cared for person is comfortable or knows how to deal with these situations.
4. The opportunity for people who are housebound with their disability to be heard – using technology positively.

BENEFITS
1. Forms should contain less jargon, as it is not always adults who need to fill them in.
2. Change the word ‘benefits’ to citizen tax credit.
3. No more fear of brown envelopes.
The Carers Parliament is organised by Carers Scotland on behalf of the Scottish Government and the National Carer Organisations.

The National Carer Organisations are Carers Scotland, the Coalition of Carers in Scotland, Carers Trust Scotland, Crossroads Caring Scotland, Minority Ethnic Carers of Older People Project (MECOPP), Shared Care Scotland and the Scottish Young Carers Services Alliance.

Carers Scotland
The Cottage
21 Pearce Street
Glasgow
G51 3UT

info@carerscotland.org
www.carerscotland.org

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