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Artwork below created on the day of the Carer’s Parliament 2015 by
Albi Taylor, Consultant Graphic Facilitator.
INTRODUCTION

Welcome to the report of the fourth Carers Parliament which was held at Murrayfield Stadium in Edinburgh on 6th October 2015. 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 contains three main sections:

1. Achievements of the Carers Parliaments

2. Report of Main Sessions
   - First Minister Speech
   - Q&A Panel
   - World Café

3. Evaluation and Carer Profiles
Including 2016, there have been five Carers Parliaments held. This gives us a good opportunity to consider what they have achieved in raising the profile of carers in Scotland and bringing key issues to the attention of the Scottish Government, statutory and third sector bodies in Scotland.

The contributions of carers at the Carers Parliament highlighted the need for new legislation to bring new rights for carers and helped shape the Carers (Scotland) Act 2016. The intention to bring forward this legislation was announced at Carers Parliament 2014 by then First Minister, Alex Salmond MSP. This Act will bring forward a range of information, support and services for carers and the commitment that carers cannot be charged for any support they receive in their own right.

Carers highlighted the need for better financial support. This and other contributions of carers in a range of forums has brought cross party consensus that Carers Allowance must be raised to at least the level of Jobseekers Allowance when powers over carers benefits are devolved to the Scottish Parliament.

Through the input of young carers within the Carers Parliaments, issues around Educational Maintenance Allowance were highlighted. This resulted in changed guidance to ensure that young carers are not penalised for any attendance difficulties they face because of their caring role.

Carers highlighted the need for better support for carers in employment and, building on the manifesto commitment in 2011, the Carer Positive Award was developed for employers that support carers. This award, administered by Carers Scotland, has so far awarded 58 employers covering almost 250,000 employees.

Two interim publications provide more details:

“Creating a Healthier Scotland – What Matters To You” report, which pulls together the key findings from our extensive six month conversation with people across Scotland about their views on the future of NHS and social care services as well as improving the health of the population.

Scotland’s new social security powers will be founded on a set of principles that treat people with dignity and respect and will be an important tool in tackling poverty and inequality. The principles reflect the feedback the Scottish Government received from organisations who work across Scotland and with all areas of society including children, carers, disabled people, ethnic minority groups and older people as well as the general public.

“Creating a Healthier Scotland – What Matters To You” report, which pulls together the key findings from our extensive six month conversation with people across Scotland about their views on the future of NHS and social care services as well as improving the health of the population.

Finally, issues raised and the discussions at all the Carers Parliaments have helped to inform policy and practice not just in the carers agenda but in the wider arenas of health and social care integration, self-directed support, short breaks and has provided carers with a voice to raise issues and inform policy decisions.
I am absolutely delighted to chair the Carers Parliament again this year. As you can see I’ve got assistance and that’s because the NHS have had their way with me a month ago but it’s been a score draw and I’m pretty much back on my feet.

I know that throughout the year ladies and gentlemen a whole deal of work goes on through organisations which represent and lobby on behalf of carers. This event however, offers a welcome opportunity to examine progress on the political front to meet and swap experiences with other carers and just as importantly to share information and news of possible opportunities. Now as I don’t have to tell you, one of the corrosive side effects of being a carer, particularly a long term carer, is the isolation it can bring in its wake. An inability just to keep the social side of your own life on track and take enough time out to keep body and soul and sanity together. So, after today, I hope everybody will be able to return to their domestic circumstances having had the chance to concentrate just for a while on their own needs and aspirations, and hopefully to be reinvigorated by the people they meet and the people they hear from. Now we’ve got a lot of observers with us today, including our friends from Wales whose intention it is to set up their own Carers Parliament to coincide with National Carers Day, so welcome to them all.

These include the huge economic savings engendered by carers, their employment prospects, their own health and wellbeing, the opportunities for education and training, and the workshops will of course cover the absolute vital areas of welfare reform and the Carers Bill. But first of all this morning we are going to hear from an Edinburgh based carer whose life changed when her mother became seriously ill. In some sense, she was a little more fortunate than some of you because she comes from a very close knit family who have also been involved in her mother’s care. But that intimacy brought its own problems both in accessing appropriate care and in tailoring that care to the particular needs of a member of an ethnic community. Please welcome Aisha Mir...
Carer Interview

Aisha Mir

My mum got diagnosed with stage 4 non-Hodgkin’s lymphoma about January last year following two or three months of very strange illnesses and occurrences and visits to the hospital. This was her third bout of cancer in twelve years. She got breast cancer about twelve years ago, recovered from that and about within a month of her getting the thumbs up from the doctor, she was diagnosed with a tumour in her liver, deteriorated rapidly within about three or four months, had to get a transplant. That was done within about a week of the timeline that the doctor had given us, made a very long, painful, successful recovery – and just when we thought we were out of the woods, she got hit with this and we found out it was a side effect of her getting the liver transplant because of her age. And this particular time, she struggled a lot emotionally and really found it difficult to deal with, unlike the previous two times as she really wasn’t very strong. This time she found it really difficult.

Ruth Wishart

Let’s just talk about what happened to your mother in the first instance and how she became ill.

Aisha Mir

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Ruth Wishart

And then she was admitted to hospital. How did that impact on you as a family because I know that you have a sister who lives quite close to you haven’t you?

Aisha Mir

Yes she lives two doors down.

Ruth Wishart

And your dad is still alive and your mum and dad live together obviously and you were still living with them, so when this bombshell hit this close knit family, how did it impact on you both individually and as a family?

Aisha Mir

Well it was the last thing we expected we just thought nobody can be that unlucky again but we are a close knit family so we support each other, but it was just the shock of ‘not again’. It had taken us so long to get over the first and then the second episodes of cancer treatment.

Ruth Wishart

It’s the treatment afterwards and the recovery that’s the hard bit. The hospital bit is so difficult, but they’re short, they’re intense. It’s the afterwards, it’s the recovery, it was just devastating, everybody just

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It’s the treatment afterwards and the recovery that’s the hard bit. The hospital bit is so difficult, but they’re short, they’re intense. It’s the afterwards, it’s the recovery, it was just devastating, everybody just
thought she’s not going to make it this time because it came on so fast, so quick and she got rushed into hospital and deteriorated so quickly.

RW I know this was obviously difficult for all of you but I think it was particularly difficult for your dad to get his head round all of this.

AM Yes dad’s old school, they are both in their late 70’s so he and my mum are like a double act. The Bouquets is the first thing I like to call them, mum as she’s a bit of a Hyacinth Bouquet. Dad’s very traditional, he’s a real man’s man. He’s not the kind of guy that will display his emotions and talk, he’s very much the man of the house and it’s his duty to carry the burden and keep everyone going.

RW Anyway you’ve got your mum in hospital and you’re there pretty much all the time in shifts and, together, you know trying to keep the show on the road and trying to keep her spirits up. But when we were talking about this earlier on, you said that in a strange way the fact that you were there all the time and visibly there all the time made it more difficult for you in terms of getting help when your mum was being discharged.

AM Yes, mum was taken poorly so quickly she found it really difficult to be in the hospital and that was the first time she had been like that so the doctors were like, try and stay and we will make arrangements, so we basically did 24 hour care in the hospital for about four months.

RW So that she would always have someone with her.

AM Yes and hospital chairs are not comfy to sleep in – I can testify. The dynamics, everything shifted, so it had such a massive impact on everybody which we are still feeling the effects of.

RW Your sister I know has got kids but you were a businesswoman, so tell me a little bit about what you were doing with your life when this happened.

AM My background was finance. I worked in the Banking Industry for about 12 years. After mum’s liver transplant, it was just such a magnanimous event for everybody. it really shook everybody’s perceptions of what life’s about. I left and then joined the family business and kind of got my teeth stuck into that but it had been difficult when I was working 9-5, managing time off and mum’s care. Working in the family business was a bit easier to some degree but equally there’s no-one to pass the buck too, so when things didn’t happen or just would not happen, the impact of that to some degree was even bigger and you’ve got staff. People were relying on you to pay mortgages, they’ve got kids, they’ve got bills, you know, so you feel that responsibility.

RW So you’re worried about that in the work and you’re worried that at home, if you spend too much time at work, you’re not spending enough time at home. So let’s go on, you’ve been on quite a long journey accessing the kind of care that was suitable for you so let’s just go through that. When you came across as to accessing care in the first instance?

AM We couldn’t get mum out of the hospital as we were too close knit a family, we were told.

We fell down the priority list with care but that was one of the issues. The consultant had to get mum home, part of the recovery, it was so apparent.

We managed to get a sort of skeleton care package from the hospital which was completely inappropriate.

Mum had gone through an intense bit of chemo. Timings, as people here know if they have people who have suffered from cancer, there is no timetable, no schedule. You’ve got to work round them and you’ve got to be ready to give them what they need when they need it.

The carers were coming in at odd times, it wasn’t their fault, they had a schedule to work to. They were coming in at odd times, mum had very strict medication to take at certain times, she had to eat or try to make her eat by that time and it just was completely out of sync. It was 20 mins here, 35 mins there and you knew it wasn’t coinciding and then the food, the diet side; they would only have time to come in and heat a tin of soup up. My mum’s Asian and you know she likes her spicy food. It was like tins of soup getting potentially lobbed about the kitchen.

RW She sounds a bit feisty your mum.

AM She’s very feisty. That’s why this episode was really difficult for all of us to deal with because to see her just literally crumble before our eyes, you know, it was really distressing for everyone, especially my dad.

RW So anyway this is not suitable for a whole wrath of reasons, not least your mum’s taste buds are not exactly being tickled. So what did you do then to try and put something else in place?

AM Through this particular social agency they quickly saw that this wasn’t appropriate. They were great and said, right, we’re not delivering what your mum needs. They eventually got an assessment made available to us. We had no clue how to do any of this, so they basically helped us get the ball rolling. We got a social worker allocated to us who was fantastic. She came out, did an assessment. Mum fell asleep within two minutes of her arriving, and she just looked at her and went, right, ok, your mum needs serious help. She managed to get us a funding package and again we were like just complete country bumpkins because we had never had to do this before, so we had no clue, totally reliant on the social worker. She got the funding and said, right, you’ve got the choice of an agency or personal assistant. I would suggest an agency because you’ve no idea what you’re doing and they’ll take care of a lot of the headache for you. We were just broken, that’s the only word I can say. The family is just emotionally broken, you are exhausted, so you’ve no idea what you’re doing and they’ll take care of a lot of the headache for you.

AM We’re looking for someone from an ethnic minority background, preferably of the same culture and religion.

Even someone from the Asian continent who has some understanding of the culture and things like that.

RW I’m just wondering before you go, it struck me that you say you just sat down and looked at everything online until you found what you were looking for, but there must be scads of people who either haven’t got access to the internet or aren’t internet savvy if they have got access?

AM I have not got a clue. I really don’t know how those people would manage. The amount of bouncing I did, you know, Mum’s having a horrendous day, not eaten for two days, she’s got to take her meds, she’s having a reaction to her meds, she’s crying, my sister is having a bit of a breakdown because she can’t cope, her daughter has taken ill, she’s in hospital. Dad’s nowhere to be seen. I’ve got this funding, I’m told I’ve got two weeks to find care and I’m trying to run a business so it’s like ‘God where do you go?’ And for people that don’t have like my family’s support and aren’t computer literate, I honestly have no clue how they would cope. I know what I went
through to get this. I literally just sat there and went Asian carers. Google search, Edinburgh and it was just coming up with nothing that was of sense and I thought there must be a data base or something I can get in touch with. It was just by absolute chance that I stumbled across the wonderful MECCOP who said yes we can help you, just pop in. In all honesty these guys were an absolute dream and I don’t think they appreciate what an impact it made.

I went down to the office, sat down with Kate who just sort of went right, give me your wish list and I thought it can’t be this easy, you know we’ve been at this for so long and in the meantime we had mum’s diagnosis, delivered the chemo, not sure if it’s cleared everything, they want to deliver more treatment but we’re scared because her health is so delicate, she’s had such a tough recovery, we’re going to wait for another scan and we’ll take it from there. That raised a whole new set of questions. If the cancer’s not gone, we just have to manage mum as it’s a kind of ‘end of life’ situation and then managing mum, managing my dad. My mum’s sister passed away, she lost two sisters this year and couldn’t attend funerals or anything like that so it’s just absolutely intense.

RW Well I’m not going to quibble with that but I didn’t mean the Welfare Reforms that we’re hoping for here, I mean the reforms to the Benefits system which have emanated from Westminster.

AM We haven’t had to deal with the Personal Independence Payments yet as we’re still on Disability Living Allowance but again that’s another hurdle that we’re going to have to face. I don’t know what’s going to happen in terms of Universal Credit. I think that’s going to be an absolute disaster. If one person in the household gets the money, what’s going to happen if you live in an abusive household? Luckily

I’ve got this funding. I’m told I’ve got two weeks to find care and I’m trying to run a business so it’s like ‘God where do you go?’ And for people that don’t have like my family’s support and aren’t computer literate, I honestly have no clue how they would cope.

I don’t because I’m a single parent but I mean it’s a can of worms or is the person in receipt of the money going to spend it on things that aren’t connected to the house. Then of course there’s the whole business anyway of having to rely on a computerised system which is usually a recipe for disaster. Apparently with the system even if you are computer literate it is very difficult so it’s going to fall on places like Vocal to help. Because of your other involvement with other carers you’ve got an opportunity to have a window into other people’s difficulties and lives.

AM I was back in the day.

RW It’s not that long ago.

AM It feels like an eternity.

RW You’re not exactly gregarious and I’m looking from a long distance. So what’s the difference between the Aisha of a few years ago and the Aisha now? What’s changed in terms of your lifestyle?

AM It’s chalk and cheese, my whole world has completely turned upside down. I remember having a social life, that was back in the day when I did a 9-5 and could actually go out and meet friends and do things. You begin to really get an appreciation just to do simple things like, I want to do my nails tonight, you know just kind of sit in front of the TV. I cannot remember the last time and this is the God’s honest truth the last time I just got my pyjamas on and just sat in front of the TV. I’ve got a great social circle, really close friends they’re brilliant, I’ve been friends with them a really long time. It’s like texts and calls. We did a little get together a few months ago, it was my birthday and they sort of dragged me out. We went to Carlisle, it was random, it was like, we’re going out, where are we going? We were at the train station and it was like, we will get on this train now.

RW I have to say Carlisle doesn’t sound like the social mecca.

AM It wasn’t, it wasn’t as such but it’s all about the company. It was just a random excuse to get away for the day and I sat there and thought I haven’t actually seen my friends for about twelve months.

RW So just think about it – it’s been a horrible experience for you and your family, but it’s probably given you a glimpse of what it’s like for people who are undergoing that kind of pressure for year upon year and sometimes decades upon decade. You probably wonder how they just manage to cope.

AM Honestly, I have intense respect for people that do this; how they cope. Through getting involved with MECCOP and getting involved with some events and things like that, I have met other carers and the isolation that you feel. And I come from a very close knit family, and if anything I’m like, give me five minutes peace, I want you to go away, I only want five minutes of me time. We are so lucky with the close family that we have got, I don’t know how some people cope. The other thing that we found very difficult and I see that this impacts on other carers, is the diversity aspect of care. There are not enough ethnic carers. That was the major stumbling block for us, we needed somebody that had some knowledge of Asian food even if they couldn’t cook it, they knew how to heat up a curry and chapatti or nan bread, because when mum got to eat it was literally just shove the food in her mouth because she’s going to not want to eat. She won’t eat in the next five minutes for the next ten hours or whatever and somebody that just understood the language was probably the hardest part in terms of the care. There’s just not enough ethnic carers in the community and I don’t understand it whether it’s Pakistani, Bangladeshi, Traveller community, there’s just not enough.

RW What’s the road ahead for you now? Where are you going from here?

AM We’ve got care for mum, it’s great, that’s been a big help. But that’s presented itself with its own set of problems and the funding we’ve got – the care is super expensive so we can only afford to get a carer for mum about 3 a day for about 4 days a week so around that we are still managing. I’m trying to recover a wee bit of my life back but that’s difficult. I’ve got a business that suffers so I’ve got things that I’ve got to look at there. We’re just hoping that mum carries...
Her health really has been good and her scans are coming through clear but she’s had a bit of a blip with medicine and things, so we’re going to have this constant. It’s going to be constant, we’re never going to get back to that point.

RW Has your dad come out the shed yet?

AM Not yet, no. We’re getting him out, coaxing him out. I bought him some new gardening tools the other day so he was well chuffed. He peeped his head out and went, oh right, a lawnmower. I’ll end up doing it but you know he will go out and play with it for a while then get bored.

RW It will be really tough for him although as well.

AM Yes it is and dad doesn’t talk, that’s the biggest thing. We all chat amongst ourselves, we all have our meltdowns, but dad will just go and sit by himself, so it’s easy to forget about people. You know like the husband, the wife, the partner – it’s very easy to forget about those members of the family. They aren’t able to vocalise about how they feel and that’s the danger with my dad.

RW And finally if you had one message for the people who are responsible for assessing carers, supporting carers, what would you say were in your, apart from the one you were mentioning about the lack of ethnic care workers, what do you think are the other gaps that you would like to see addressed.

AM I just don’t feel there’s enough understanding about what it’s like. The recovery, it’s this period for me having been through this. This is the hardest part of the journey. You’ve been in the hospital where you have the doctors and nurses available. When mum was critical, to some degree that was easier to manage because everybody was there. It was important, it was urgent, she was a priority. Now she’s in a kind of no-man’s land where she’s not recovered, she needs the support, she needs the care. That’s the gap, it just feels like the funding’s given, projects are ruled out, but the minute you get one person or one situation that doesn’t fit or there’s abuse of the system, they remove the funding completely. It’s not broken, it needs tweaking. You need to get into the grit and the bones of the cases, of the families and see how it’s impacting. But it’s this period now. For me I think this is the hardest, this is the bit that’s looked at the least.

RW OK. Ladies and Gentlemen, Aisha Mir.
WORKSHOPS REPORT

"CARERS SHAPING THE FUTURE"

Scotland is going through a period of significant change politically and many of these changes will affect carers. And within the next two years we will have both a Scottish Parliamentary Election and a Local Government Election within which carers voices should be heard.

Carers within each of the workshops were asked to consider:

What are the key issues in relation to the topic which affect your life as a carer?

What can Government, the NHS, local authorities and the third sector learn from carers' experiences to improve this?

What are the key priorities for future action that would improve your life as a carer?

TOPIC 1

Fairer Scotland: Social security and carers, devolution of carers financial support

Carers within the workshops highlighted the following issues:

• There is a disparity between the level of benefits provided to parent carers as opposed to kinship carers

• The rules around Carers Allowance limits it to only certain carers:
  • Carers Allowance stops with pension but care still the same. There is no recognition for carers who receive the state pension. Expenses of caring still remain for older carers which impacts on carers finances alongside health issues for older carers. Carers Allowance should be available for carers of all ages, tied to caring role, not age
  • Young carers lose Carers Allowance when they go to college or university full time. Full time study can be defined as at least 3 days per week. Carers in education have the same duties but receive no Carers Allowance. There is a lack of support for student carers in further education and a gap in support for young adult carers in general. Support groups withdrawn at 16 and there is a gap between ages 16–24. Local authorities need to raise standards and provide consistency and parity across councils
  • Carers can only receive Carers Allowance for caring for one person. There is no recognition of carers who care for more than one person, e.g. a parent of two disabled children
  • Delays in disability benefits create difficulties for carers. Sometimes this is linked to waiting for a diagnosis which delays payment of benefits for considerable periods, sometimes years
  • Charging for care services causes problems for the whole household. During the discussion it was highlighted that there is no parity in charging. Disabled people aged 16–64 cannot receive free personal care and their charging threshold is lower than people aged 65 and over
  • Recognising the needs of people who only have the basic state pension because they have provided care during working life
  • Carers Allowance should be non means tested and not treated as income in either Scottish or UK social security systems

• UK Government should devolve all benefits and end work focused interviews

• The Scottish government should link new support (benefit) to level of care provided

• Long term conditions should be exempted from need for further applications

• Scottish Government should establish a national agency for social care provision/department for caring

• The NHS should improve systems and recording to help planning of services

• Scottish Government should end local authority discretion in social care provision

• Scottish government should put timeframe in Carers Bill for local authorities to carry out carers assessment

• NHS should improve the provision of specialist services for long term conditions

• Scottish government and local authorities should link effective assessments to accessing carers benefits

KEY ACTIONS

1. Need a national framework for carers. Carers need to be involved, including in developing forms to apply for benefits. A steering group should be established.

2. Identifying and ensuring that carers in Scotland, including hidden carers, are reached and referred to support, including financial support. Carers centres are good support.

3. Provide help with other costs that carers face. For example, carers should be entitled to concessionary travel.
TOPIC 2
Valuing Carers Economic Contribution: supporting carers into employment

Carers within the workshops highlighted:

- Flexibility is key and need new models of employment. Noted that, whilst zero hours contracts are viewed as bad, they could be viewed as empowering for carers - not necessarily a black and white issue but helpful if the Government could firm up employment rights for those on zero hours contracts
- Raising awareness amongst employers vitally important
- The earnings limit under Carers Allowance penalises all carers in employment, including young carers in apprenticeships

- Carers need more advice and information on employment options
- Carers being able to access or sustain work need good access to support and services.
- Planning for emergencies important

KEY ACTIONS
FOR YOUNG ADULT CARERS
1. Lower the age of carers allowance and recognise that it can be difficult for young carers to get jobs. They need better employability support and local support from groups. Better local employer links with financial support and incentives to employ young carers, would be helpful and the ability to factor in Educational Maintenance Allowance.
2. Need protection against discrimination to enter employment, including understanding and flexibility from employers. Good employers are beneficial but also need good support from the NHS and local authorities. Could a carers register help protect those in employment?

FOR ALL CARERS
1. Promoting flexible working and employment rights for adults and young carers.
2. Better partnership working with Health & Social Care services to support people into employment.
3. Better support at an earlier age.

TOPIC 3
A Bill for Scotland’s Carers

The Group were asked how the following stakeholders should contribute to the successful implementation of the Carers Bill.

The information below lists key messages for different authorities and Government.

LOCAL AUTHORITIES
Key Message: It’s the Law, fulfil your duties and invest in carer services

- There is a lack of services. If services, such as short breaks are not there then what difference will new rights make. There needs to be appropriate services for the carer and cared for
- There should be a national minimum entitlement to support
- Better planning for transitions
- The Bill needs to bring in a statutory duty for Local Authorities to support carers
- There needs to be better support for young carers, at an earlier age. Some young carer projects start at 8
- There were concerns that LAs would ignore the new duties
- Local Authorities must involve the 3rd sector and carer support organisations in implementing the new duties. Some of the duties should be devolved to the 3rd sector and they should be funded to fulfil them
- Local authorities need to involve carers fully in implementing new duties locally
- Emergency planning must be part of the Bill
- Waiving charges regulations should remain the same
- The Bill sets out the duty to ‘inform carers’ this wording is weak. It should be services should be ‘informed and led’ by carers
- The duties to involve carers in strategic planning should be built on. Carers should have an equal voice with LA and Health reps
- Once the new duties in the Carers Bill are in place LAs should inform carers of their rights and the process for accessing their rights. This should include timescales and the process for appeal
- To ensure carers know their rights there should be a carers pack, or carers passport. This should be written by carers

HEALTH
Key Message: Good partnership working is needed to make it work

- Don’t hide behind confidentiality when it comes to carer involvement
- Listen to carers
- Carers need to be equal partners with health professionals
- Hospital discharge needs to improve – involve and listen to carers and there should be no time lapse from someone leaving hospital to having care put in place

THIRD SECTOR
Key Message: Fully involve the third sector in the implementation of the Bill and fund them to play their part

- There is a need for advocacy support to assist carers to get their rights and to support carers where there is a disagreement with the LA. For example, in relation to eligibility

CENTRAL GOVERNMENT
Key Message: The Carers Bill needs to be fully funded

- Implement a national minimum eligibility for carer support
- Police the Carers Bill
- Set up independent monitoring to evaluate it
- Monitoring needs to have teeth – a voluntary code of practice will not be sufficient
- There should be a Minister for Carers

Lower the age of carers allowance and recognise that it can be difficult for young carers to get jobs.
TOPIC 4
Improving carers health and wellbeing

Carers within this workshop highlighted:

- Carers neglect own health especially working carers
- Don’t give yourself permission to look after yourself
- Prevention of accidents and injury are key
- Carers feel responsible and not able to ask for help from those around them
- Carers feel isolated, regardless of people around them. This leads to stress
- Friends/support network not necessarily aware of help you need. Be good to ask for what you need. Providing practical support for carer is important but they don’t necessarily know what support to provide or might not be the right people to give support. Family/friends might not necessarily be the right people. Sometimes it’s good to speak to others who understand – who aren’t family or friends
- Need one professional to take control of everything – not multiple professionals. Difficult to navigate your way round the system. Single point of contact is needed. At 18 years, single point of contact stops
- Constant traffic through home of different disciplines is stressful
- Budget cuts are stopping/limiting services. if you ask for help you are pushed round all the services. Services need to listen
- Voluntary service has a role – a big part. Offer practical and emotional support. Can offer a different kind of support. Give more power to the voluntary sector. Qualified staff in their experience which is good/essential but this isn’t the same everywhere, not consistent
- When something happens to carer’s health – not sufficient support – no respite given, assessment useless. Once carer noted they had a heart attack and received no respite, no help, no proper support for daughter. Assessment didn’t address carer’s needs and it had been 6 years since last assessment
- Respite is essential for a carer. Easier access to respite and the right kind of support offered
- More regular carer’s assessment – “being cared for” assessment. Assessment process needs improved. Bureaucracy is a big problem. Need to simplify the process

- Self-assessment process could be helpful – what is relevant to you – and have ability to monitor and update
- Support services not working for individual’s needs. Geography a problem
- Education needs to work with the carer and family as does housing. Professionals don’t “speak” to each other. Too much passing the buck amongst services. Money is the issue not peoples actual needs
- System sometimes forces people to move their home to provide the right care, education for children etc. but who pays for these moves?
- Professionals need to get together at a time to suit carer and cared for person. One key person is useful
- Simplify bureaucracy. State clearly what a carer can and can’t expect and don’t pass the buck. There is a need for real conversation about this with more honesty. Carers know best what can be given, not services and need better faith in system. A system that doesn’t make them jump through hoops
- Social workers allocated to a GP surgery to improve communication between disciplines/departments. Integration processes need to be supported but also simplified
- Carer investment needed – emotional support, sounding board, respite, better understanding of conditions. Services need to speak for the person – be more relevant to circumstances. The right kind of help/support – person centred services

KEY ACTIONS
1. Single point of contact to coordinate services for a carer.
2. Importance of respite and right kind of respite. Person-centred support which should come out in carer assessment (not necessarily person-centred currently).
3. Voluntary services need more power.

TOPIC 5
After caring: looking to the future

Carers within this workshop highlighted:

- Getting back into work after a gap. There is no real advice for former carers to get back into work. Consider tax incentives to support carers back into work and what training and support for carers looking to return to work
- Want to maintain employment skills but carers offered no training
- Employers support to maintain carers in work. Carers often need or want to work and shouldn’t be penalised
- The short period before Carers Allowance is stopped after caring ends is a problem
- Lifting some of the restrictions on Carers Allowance to allow part time work would be helpful
- Lack of education about what carers do and who they are from statutory services e.g. education, schools and teachers, GPs and job centres. Not enough information on hospital discharge. Not enough to support people make decisions about care, support and help
- Culture change
- Feeling being dropped following caring role by organisations. Former carers feel there is nothing organised for people when caring ends. Support groups lost, sense of purpose lost. Often sense of guilt following transition to care homes – more support needed – one to one. The caring role may have changed but not finished
- Former carers have a lot to offer – need to feel valued – lots of experience to share – peer support
- If you don’t know to ask or what to ask – seeking and searching for info whilst caring
- Consider a tax allowance for paying car home fees – nothing tax deductible
- Need secure funding for carers services over 2016-21 Scottish Parliament and beyond
- Emergency financial support
- Support for carers to get ‘lives’ back after caring e.g. a post caring support plan with a personal outcome focus
- Proper bereavement support needed but availability limited

KEY ACTIONS
1. Support for carers to maintain employment and for those who cannot stay in employment, to maintain their employment related skills. Carers need help and support to get back into the workplace.
2. Post caring support and planning is needed to help carers manage transition and to plan for their next steps. Support and recognition of carers whose loved one has moved to a care home. Recognising the difficulties and issues and continuing support.
3. Valuing and utilising the experience and knowledge of former carers.
TOPIC 6
Improving opportunities for carers education and training

Carers within this workshop highlighted:

• Widening access and improving retention in further education
• Carer specific training – lack of national support in rural areas for support
• Places on carer’s specific training – money, resources and time
• Proper training for carers should be available which is recognised/certificated
• Not receiving help from schools even where schools know someone is a carer
• Lack of places for access spaces/flexible course. Need more flexible routes to education
• Transport to alternative forms of education would be useful
• Listen/Case studies – need to be heard
• Provide a dedicated worker in schools, colleges and universities for young carers/young adult carers
• Skills and transition when caring ends – what’s out there for carers post caring – support
• Carers’ benefits must have national guidance
• More personalised student support needed
• Easier access for carers for public transport – eg concessionary travel
• Training needed for teachers on carers issues
• Access to vocational courses/apprenticeships should be available to all ages
• Implementing GIRFEC for everyone up to 25 years old
• Politicians and decision makers speaking to carers and reaching out – NHS, GPs, Carer organisations
• Better financial support for student carers
• Carers assessment promotion of education to all carers and action taken and adequate support
• Carer friendly training establishment

KEY ACTIONS
1. Widening access and improving retention in further education. This includes, for example, providing dedicated support workers, improved funding and help with transport.
2. Consider providing carer training which is recognised and certificated.
3. Improved training for teachers and better support in schools needed.
FIRST MINISTER, NICOLA STURGEON MSP

Introduced by Ruth Wishart

RW: Ladies and Gentlemen, welcome back from the workshops, I hope all your deliberations were fruitful, we’ll get feedback on them later on and I hope you’ve all got sharp questions for the panel that’ll be arriving after lunch.

Now is the main event, it’s our keynote speaker and today it’s a woman whose very first engagement, as First Minister of Scotland, was in fact to meet with a group of carers at Bute House, that rather nice address in Charlotte Square which comes with the job. There are a lot of other strings attached to that employment, non-stop scrutiny, alarming working hours, and not least, non-stop engagements in addition to leading her party in Holyrood. We are delighted that once again, she’s underlined her commitment to an interest in Scotland’s army of carers, by coming to give today’s keynote address.

Please welcome the First Minister of Scotland, Nicola Sturgeon.

Thank you very much indeed Ruth for that introduction and thank you to all of you for inviting me here today and giving me the opportunity to deliver this keynote address.

It is a huge pleasure for me to be here today. As Ruth said very deliberately the first official event I undertook the day after becoming First Minister, was to meet with a group of carers and I hope that, that underlined and continues to underpin the importance, not just me, but the whole Government attaches, to the very difficult issues that all of you as carers and the many thousands of carers across Scotland, deal with on a day to day basis.

It’s a pleasure to attend this fourth Carers Parliament. I’m very grateful to Simon Hodgson and everyone at Carers Scotland for organising it.

In total, there are more than three quarters of a million adult carers in Scotland, and a further 30,000 who are under the age of 16. That’s enough to fill the stadium here more than 11 times over.

That demonstrates two things. The first is the sheer scale of the contribution that carers make to our society and to our economy.

In total, there are more than three quarters of a million adult carers in Scotland, and a further 30,000 who are under the age of 16. That’s enough to fill the stadium here more than 11 times over.

And the second point is that, depending on life circumstances – for example the health and wellbeing of our loved ones – caring is a role that anybody could feel required to take on. In fact it’s been estimated that 3 in 5 people in Scotland will become a carer for a loved one or family member at some point in their lives.

However, we also know that caring is a responsibility which is likely to fall most heavily on people who need some extra support. For example, research suggests that a disproportionate number of full-time carers live in deprived areas, and have health problems or disabilities.

So improving the support we make available to carers helps individuals and families across the country. And it brings the biggest benefits, to those who need the most help.

That’s why, when this government came into office, we made 11 different manifesto commitments relating to carers and young carers. Establishing this parliament was one of them.

Through the Equal Partners in Care initiative, we’ve worked with the NHS and social care professionals to improve how they work with carers and young carers. We’ve also significantly increased funding for short breaks, information and advice services, and other support services.

The voluntary sector Short Breaks Fund allows over fifteen thousand carers and cared for people to take a break - giving them an opportunity to relax without feeling stress or guilt. That’s the sort of practical step which can make a major difference to people’s quality of life.

We also know that caring is a responsibility which is likely to fall most heavily on people who need some extra support. For example, research suggests that a disproportionate number of full-time carers live in deprived areas, and have health problems or disabilities.
We know that caring responsibilities can cause or exacerbate mental stress and physical illness. By enabling people to ask for a support plan as soon as they become a carer, the Bill can help us get the support that carers need, to them, as quickly as possible. That means we can reduce the need to deal with crisis situations such as serious illness that often befalls a carer just because the caring responsibility is putting them under so much pressure.

And the final point about the Carers Bill is that we have been listening very carefully to the views that people have expressed on the Bill. I know that most carers see the Bill as a big step forward, but there are areas where they would like to see it go further. I absolutely understand that. So we are determined, as we go through this process, to continue to listen as carefully as we can, so that we are taking any opportunity that we can to improve that Bill further.

One issue that has been raised is a good example of that. That is the issue of emergency planning. Many of you have said to us that you want the Bill to make it clear that emergency planning – thinking about what happens when a carer is unavailable – should be a fundamental part of the carer planning process. We have considered those views and we agree – and so I can confirm today that we will propose amendments to the Bill to ensure that emergency planning is discussed as part of that process.

I can also confirm today that we will use regulations to ensure that carers cannot be charged for the support they receive. That includes in cases when replacement care is needed.

After all, we know that carers understandably sometimes need a break from caring. It’s important that they know they won’t be charged as a result of that, when someone has to step in and do the caring for you.

I hope, that both of these steps will provide additional assurance for carers and the people you care for.

I hope as well as being meaningful and important steps in their own right, they demonstrate something more general, and that is that, when we do hear good ideas for improving the Bill or the regulations that will flow from the Bill, we will, wherever we possibly can, take them on board. That is, I hope, me demonstrating an action. What I said earlier on, we want to continue to work with you on an ongoing basis to improve the support that we give.

Through all of this, we will, I believe, be able to make sure that the Bill is a significant statement of our commitment to carers. It will strengthen their rights, improve their support and enhance their wellbeing. I think that’s something we can all welcome.

Finally on that point, it wouldn’t have even got to this stage without the hugely valuable contribution from you and other carers from across the country, and again that demonstrates powerfully the value of forums like this, and the regular engagement and dialogue that we have.

The second issue I want to talk about is how we intend to use new social security responsibilities when they are transferred from Westminster to the Scottish Parliament.

As many of you will know, these responsibilities – we don’t know yet when they will be transferred – include the Carers Allowance, which helps individuals who look after someone with significant caring needs.

We’re determined to ensure that the Allowance, when we take responsibility for it – like our new social security system as a whole – better meets people’s needs, addresses their priorities and respects their rights. I am on record saying and I continue to believe that it is wrong that carers’ allowance is one of the lowest benefits, if not the lowest benefit that we pay in this country.
It should be, at least, at the level of jobseekers’ allowance. So that’s one thing we’ve said should be done to make the allowance fairer. But there are other things that we need to do, particularly around eligibility. There’s still two things that we need to get assurances on from the Westminster Government.

Firstly, that the financial settlement for transferring responsibilities is fair and does not have a detrimental impact on the budget of the Scottish Government.

Secondly, it’s about making sure that the additional powers that are transferred are full enough to allow us to make the carers’ allowance as fair as we want it to be. Right now, the way that those powers are being drafted, that isn’t the case. At present, the UK Government’s proposals, and they would remain in charge of this, define who should be considered as a carer. The Scottish Parliament, as things stand at the moment, can only make minor changes to the definition of a carer.

I think that is completely contrary to what was proposed by the Smith Commission. I think the ability to define who is a carer should rest with the Scottish Parliament, not with the Westminster Parliament.

That’s not a narrow or technical constitutional point. The definition of a carer has real consequences for who can benefit from carers’ allowance. One good example of this is the current UK definition that includes the requirement that a carer cannot be in full-time education. What that means is potentially that a carer, if they want not to lose their entitlement to carers’ allowance, can’t go into education to develop new skills to help them get into a job and fulfil their potential.

It’s a good example of why the Scottish Parliament needs the ability to determine who receives the allowance. It’s the only way in which we can fully achieve a fairer and more effective system. That’s why we are calling for there to be amendments to the Scotland Bill before it completes its passage, to pass that responsibility to the Scottish Parliament as well.

I am on record as saying and I continue to believe that it is wrong that carers’ allowance is one of the lowest benefits, if not the lowest benefit that we pay in this country. It should be, at least, at the level of jobseekers’ allowance.

I said at the start of my speech that approximately 3 in every 5 of the population are likely to be a carer at some point in their lives. That does demonstrate that the issues that you’re talking about today are not niche issues that just impact on a discreet section of the population. These are issues that will touch, at some point in the coming decade, upon virtually every household in the country. That’s how important these discussions are.

That’s why this Government is so determined, not just to maintain, but where we can, enhance the existing support we give to carers. It’s why we are so determined to continue to improve the Carers Bill and work with carers to implement it effectively. And it’s why we are determined to get as many new powers in this area that we can and then to implement those new powers wisely and well.

We want to make sure that the significant improvements that we have seen in recent years are just a starting point, in delivering better support for hundreds of thousands of carers across the country.

And in all of this, of course, we’ll continue to work with individual carers and carers’ organisations as closely as we can. That is exactly why events like this are so hugely important. They are important to you I know, to come here, to come together and discuss these issues, but I want to end by telling you how important they are to us in Government as well. So thank you very much for giving me the opportunity to share our thoughts with you today. Jamie Hepburn, the Minister responsible, will be here this afternoon to take part in the panel, so make sure you’ve got some really tough questions for him later on. Thank you, for all that you do and thank you for being prepared to work with us as we try to provide the support that you so richly deserve.

And it’s why I look forward to working with all of you, in the months and years ahead.
Good afternoon ladies and gentlemen, if you would all just take your seats now please, we are ready to roll.

You’ve all provided questions and you’ve all provided very good questions but the sad fact of the chronology of the day is that we won’t get through all of them. But what I can promise you however is that the responses to the questions will be included in the report back which you will get. We’ll get through as many as we can but what we’ve done is try and cover as broad a spectrum of issues as possible, so if your own question isn’t flagged up I’m sure these ones will be of interest to you.

First of all, let me introduce you to what is a very high profile panel so there’s no question of you missing them and hitting the wall.

On my immediate left is Jamie Hepburn, MSP for Cumbernauld and Kilsyth, he’s also the Minister for Sport, Health Improvement and Mental Health. When he was a very young man, as opposed to the quite young man he is now, he was a doorman at the Glasgow Citizens Theatre. The Glasgow Citizens Theatre has just celebrated its 70th birthday.

On my far right is Elaine Torrance who is the Chief Social Work Officer for the Borders Council. She is also convener of Social Work Scotland’s Community Care Standing Committee.

On my immediate right is Peter Johnston who is from Dundee, but as those of us from Glasgow say you have to start somewhere. He has served as leader of two West Lothian administrations and in 2012 he was elected as the CoSLA spokesperson for Health and Wellbeing. Please welcome them all.

All of that was just to make sure they didn’t get ideas above their station. You know what panels can be like, don’t you?

Anyway, we’ve hopefully got the people who are going to put these questions to the body of the Kirk and the first one is coming from Helena Kelman, if you can identify yourself.
“I just wanted to know what the panels want to say regarding the Post Code Lotteries, in respect of Self Directed Support and also funding in general for care provision. There’s currently a disparity amongst Local Authorities and that was very clear last year at the Carers Parliament and it still seems to be the same issue, and we would like the Government to actually look at how they can actually give more, or enforce more, to the Local Authorities. I would just like some kind of answer on that.”

Ruth Wishart Thank you very much Helena. I think we’ll start with you on that one Peter since it’s very much a CoSLA issue.

Peter Johnston Thank you.

I think the Postcode Lottery question raises a number of concerns but it’s a big picture and there are a number of issues that you have to look at.

I think we would firstly say that I think the days of trying to deliver a ‘one size fits all’ service are over and from a CoSLA perspective we start from a premise that we see carers as equal partners. We want them to be involved in shaping the services that we are going to deliver and that means that we need local flexibility to get down to a local level, to deliver what is best to meet the needs of individuals within their community. Of course we recognise that every community is different and the ability and the need, and how you deliver services in Oban or in my new hometown of Livingston is completely different. So you are not going to get a ‘one size fits all’ solution. What you have to have is think is consistency in delivering outcomes, that’s the result for people and we all want to see better outcomes for carers and those they are caring for. I don’t think we can achieve that by simply looking to have, what people would call the elimination of Postcode Lotteries and essentially everything being the same everywhere. I don’t think that’s the solution and we would certainly not advocate that. So what I think I’m saying to you is consistency and outcomes for people. People shouldn’t have different outcomes but different ways of delivering that. And we recognise that we need to deliver that with carers at the heart of the service delivery, design, with carers having an equal voice, a voice that is listened to and taken on board as they shape the services that are delivered in their locality. Ruth Wishart I think Peter, that while everybody would agree that you can’t have a ‘one size fits all’ package depending whether its rural or urban etc, I think most carers, what they are looking for however is fiscal parity. They don’t want to be financially disadvantaged from one area to another.

Peter Johnston I understand that but then again the cost of delivering services varies from locality to locality for quite legitimate reasons. Rural areas are different from urban areas and what I think we can accept is that we certainly have to work harder at understanding why there may be differences, and that we need to share best practice and get better at doing that. I don’t think we would want to or would value being driven towards no differences and no option to have local flexibility with people at the local level determining the service provision. We think that the best decisions will be made by people who are most aware of the circumstances that their locality requires to be addressed. Ruth Wishart But you wouldn’t want them to be financially penalised for choosing to live, for instance, to live in a remote area.

Peter Johnston Absolutely not, we want the same outcome for individuals. I think that’s what I’m clearly trying to say. You might have to do different things to deliver that outcome but we definitely want people to have equality of outcome.

Jamie Hepburn Thanks Ruth, I suppose the first point I would make is a general one about Self Directed Support. I’m a great supporter of the philosophy behind it. I think it’s based on principles of empowerment, promoting greater independence by its very nature. That will, I suppose lead to different approaches being taken, not just in different areas but by different individuals who are in receipt of Self Directed Support. Where I would agree with Peter is the point that we should always be seeking to learn the best practice, so where one area has adopted particularly good practice I think it’s incumbent on other local authorities to seek to learn from that. Perhaps there is a role for us as a Government to consider how we can better facilitate that and I’m also willing to take that on board. I understand through the First Minister, and what I understand was a very well received address to you this morning, was very much emphasising the issue of rights. Rights for people in general, but certainly rights for carers and of course, one of the things that people have a right to now is Self Directed Support. They also have a right not to be in receipt of it. We will always take that rights based approach. If there are issues happening on the ground then we will be keen to hear that and seek to fine-tune the roll out of the Self Directed Support.

But I think the basic premise of it as a means of delivering funding to individuals is a good one, and I would very much emphasise the point that Peter has made, we should always be seeking to learn best practice from area to area.

Ruth Wishart Can I ask you, I know the Carers Bill is still making its way through Parliament and of course there are amendments being discussed. Just on a personal level without committing your Government, but on a personal level, how do you feel about the principle of there being a duty on Local Authorities to provide carers support rather than a discrentional payment?

Jamie Hepburn I better be careful in what I say. Clearly, I think the Carers Bill is an important advance for the rights of carers, it will be when it’s passed through Parliament. There will be duties on Local Authorities to offer a carers support plan or a young carers statement to every carer who is identified or comes forward who wants to go through that process. It’s very much a person centred approach around the individual needs of that carer. I think that’s a sensible approach.

Ruth Wishart It should be a duty.

Jamie Hepburn Under the terms of the legislation, it is incumbent on Local Authorities to go through that process where carers are identified and come forward and seek to go through that process. So you could call that a duty. I suppose the point I’m making is it’s very much around the individual needs of that care and I think that tallies very neatly with our approach to Self Directed Support to try and get the most for the individual. No individual circumstances are the same as the next and I think that’s the sensible way forward.

Ruth Wishart Miles Mark, you’re in the middle of a huge region. NHS Highland has got a ridiculous amount of land mass to cover so I suppose you’ll be well aware of the fact that it’s not interchangeable for instance with the inner city urban needs, but how do you see the Postcode Lottery working out or not in your area?

Miles Mack I see this as incredibly difficult and I know from my own experiences of the GP contract in 2004, which tried to distribute resources as they’re most needed, how desperate that could become. I don’t think it’s easy because it’s very difficult to get a measure of that. In my own practice I’ve got some of my patients who are an hour’s drive away, others only a few minutes from Inverness, with its modern district general hospital. I can’t say it’s easy to do on an age/sex basis because I’m well aware that in some parts of Glasgow people rarely live as long as they are expecting around my area of Inverness or some other parts of Glasgow and those people who are dying early, before their time obviously have huge needs as carers from health and social care system. So any measure seems to be fraught with difficulty, how on earth the Scottish Government unravels that is difficult and has got my sympathy. Certainly from rural areas the problems are huge, the numbers of people out there to provide the care are very limited, very restricted, particularly in social care, who’s available to...
Social care is very much your bag Elaine so how, not just in the Borders but in terms of pan Scotland approach can you deliver across such a wide and complex difference of areas?

Elaine Torrance I think I agree with Peter about outcomes and needing to make sure that we can measure outcomes and hear how effective we are in terms of delivering services to carers and I think we need to get better at that. We need to be asking people more effectively what the services are doing for them and how they need to change by working together with carers and if we need to make changes to the services that we are providing it needs to be done in a co-production, a joint model of working together. We have got challenges in the social care sector; we know we have challenges around the kind of resources that we have available. We have challenges around recruitment and retention, around staff which we are trying to address along with other colleagues here but we have to get better at hearing what works, what the outcomes are, being able to develop more personalised and individualised packages that are flexible and I don’t think just the same services in the same area uniformly will actually fit the bill for everybody so we need to be working together to think about a comprehensive approach to this.

Ruth Wishart We are going to take the second question now which comes from Rob Kaye and if you could put your hand up and the Mike will get to you.

So any measure seems to be fraught with difficulty, how on earth the Scottish Government unravels that is difficult and has got my sympathy. Certainly from rural areas there are huge numbers of people out there to provide the care are very limited, very restricted, particularly in social care, who’s available to care in some of the most remote areas.

Ruth Wishart Well some of them are employers and some of them are not so let’s start with Miles Mack this time.

Miles Mack Can I just clarify the question? Are these carers who we are dealing with as partners, or carers with my practice?

Rob Kaye I think primarily in the first place because actually if you look at the organisations represented there, it covers quite a lot of work across Scotland, but I think it also reflects a wider constituency of people who you provide a service to.

Miles Mack My practice is independent of the NHS, as are the vast majority of practices across Scotland that we are all contracted to provide services to the NHS and so our employment matters are held within our practice. As a result of that sometimes it has two effects. One part of it is that we don’t have the large HR resources that are necessary to manage some of these problems, but the advantage is we’ve got flexibility. Our practice managers know our staff well and it’s hugely in our interest, and each individual’s, interest to follow best practice to make sure our staff meet their commitments in their own homes, in their own lives, as well as meeting the needs of their patients. So that’s how I would see it, but it would be something to do with how each of the practices is run. On the wider issue, I think probably even more relevant and I’m really delighted to be asked here. I’m really glad that carers have got such a strong voice because I’m well aware that all of my members are well aware of the huge amount of effort and time, and how it transforms patients’ lives, what carers can input. We interact as partners so we’re hopefully working alongside you to try and co-produce a really good outcome for our patients and hopefully we get to know you and can be accessible to do that. Although I’m well aware that our organisation at the moment is under a great deal of strain as far as workload and workforce, my apologies if we’ve not been able to be as available as we would like to. We also know you as patients, you are patients and we have to bear that in mind when we’re seeing you, that actually carers have unique situations, unique stresses on them and that’s something that’s crucial as well. Hopefully some of the work that we’ve done through our patients group has been to try and make sure that our wider membership is aware of what is available for carers, that the resources are there and we’ll do the best we can to trickle down that information.

Ruth Wishart Thank you very much.

Elaine Torrance Thank you. I think as local authority employers we’ve moved a long way in a very positive direction about supporting carers in employment. Certainly there is much more emphasis on flexible working, giving people time off for hospital appointments to accompany family members etc, people being able to come in late, finish early, to help to support the carer and the carers needs.
That’s really important and I try hard to be promoting that in terms of the work that I do, not just nationally, but locally.

Peter Johnston Yes well I think from a CoSLA perspective we start by absolutely recognising that carers have a right to be in employment and should be supported to retain employment, and, as Elaine has indicated we within the local government family do all we can to support carers in employment. Local authorities are significant employers so they offer a range of employment opportunities and within that, we’d look to deliver flexible support tailored to the needs of an individual carer, to allow them to maintain their dual roles and responsibilities. We also try and share what we consider best practice in the rest of the public sector and across those that we look to procure services from, although of course we don’t have the powers to enforce what we do in local government upon those that we’re looking to procure services from currently.

Jamie Hepburn Thanks Ruth. First of all, I should say it’s good to see Rob Kaye, my constituent here asking me this question. I suppose I’ve got to answer this in two ways. First of all as the Scottish Government of course is an employer and as the Minister with responsibility for carers policy, it is my clear expectation that the Government would be a carer friendly employer. I’ve not heard anything to suggest that’s not the case and if I did, I would certainly be pursuing that, so it would be my expectation as an employer the Government would be carer friendly.

However, of course, we have the wider responsibility to try and facilitate carer friendly policies on a wider basis. And of course one of the things that we took forward, not only was this Carers Parliament a Government manifesto commitment, so was the Carer Positive Award Initiative which we are very delighted to have implemented and to see rolled out. There are 33 organisations who are signed up to that, there are another 60 who have expressed interest in becoming involved so around 94,000 employees in Scotland are currently benefiting from that scheme. That’s good, I think that’s progress. I don’t think it’s good enough and you can be assured we will continue to push that scheme. The other things that are of course important we think, in particular to our younger individuals making sure they get the best start in life so that they can get the employment opportunities, one of the things that we as an administration have done is protect Educational Maintenance Allowance (EMA), which we have seen under attack in other parts of the United Kingdom. I know there has always been issues about young carers and their experience through schools and colleges, having issues in terms of their attendance and being able to access Employment Maintenance Allowance (EMA). Last year and the then Minister for Public Health and the Education Minister wrote to all education authorities to remind them that they should adopt a flexible attitude to young carers so that they can benefit from EMA. I know that there are still issues out there and that’s something I’m aware of and will continue to look at. Of course I’ll always bring it back to the Carers Bill, one of my last answers. The Carers Bill is about very much a person centred approach and, as part of any adult support plan where there are issues of employment, I would expect that support plan to try and help, if it’s the expressed wish of the carer to maintain their employment. So these are things that we are doing and we seek to do and of course if there are other good suggestions out there, we are always willing to listen to them.

Ruth Wishart As you know, the Carers Parliament comes but once a year so Christina Boyd has obviously decided to get her money’s worth and is asking two different questions which we are going to allow with a special dispensation.

carer and the carers needs. We try to be exemplar employers wherever we can, perhaps don’t get it right all of the time but we certainly try and do that. I suppose I also see as rolling commissioning services, we try to encourage other organisations who are working alongside us to have a similar kind of approach. I think it’s always difficult sitting on a panel like this because we all sit here with lots of hats on so I’m here, I’m a chief social work officer, I’m also a carer in my own rights. I have a brother with mental health needs. I’m actually grappling with that as well as quite a busy role for myself so I absolutely appreciate the need for that flexibility for the time to do the things that you need to do, because if I’m going to ring his day care centre I need to ring it during the day so I need to be able to do that in work time. You know I think we’re all sitting with lots of different hats on here and I think that’s helpful when you try to be a good employer because you’ve got those experiences and you’re mindful of that. And I think
“This is like Tesco, buy one get one free. First of all, about the Carer Bill. How would you resource this and how are you going to fund it? Particularly in light of some of the statements that have been made by the Health and Sport Committee who have been looking at the Bill, saying they are concerned about funding.

And also to Local Government, how are you going to prioritise investing in carers support and use existing resources? Would you ring-fence it? Money’s tight, nobody is looking for everybody to start blaming everybody else about the lack of money. The reality is, if you spend money on carers there’s less money for education, roads and libraries. All these people are going to lobby you. How are we going to get money spent on carers locally and what about resourcing fully the Carers Bill?”

Ruth Wishart Thank you very much. Well with apologies to Elaine and Miles, I’ll just put that directly to the two people you have addressed with these questions. So first of all the Minister, how are you going to resource the Carers Bill?

Jami Hepburn Well, we’ll resource it the same way that we would resource any Government legislation would resource it through our blocked grant. We have set out our best estimates of what we expect the cost of the Bill to be. It’s a substantial amount.

It rises to around £80m, I think and if the officials are here they will correct me if I’m wrong, later. I think in the financial year 21/22, that’s based on all the available information that we have. Of course, I’m aware, as you clearly are, of the Health and Sport Committee’s report, we will respond to that in due course. It’s part of the legislative process, they publish a report. Any committee publish a report at stage one of the Bill process. We’ll respond to that in due course, but we’re working with our colleagues to make sure that all our assumptions around the costs are as accurate as they can be. We’ve set up a finance group with our colleagues in CoSLA and indeed also the Carers Organisations are represented in that group. They continue to work through at our assumptions but right now I’m still standing behind that financial memorandum. We’ve set out what we expect it to cost and will provide the necessary resource. When we legislate for anything we seek to fully fund it.

Ruth Wishart You do know that John Swinney’s spies are everywhere.

This question Peter was specifically for you. We all know that there is a challenge coming down the track in all Local Authorities because of various reductions in available funding, but very specifically, are you going to ring-fence any new monies and hold onto existing resources for carers support?

Peter Johnston Well I think the first thing I should say Ruth, is we do work with the Scottish Government. We have a commitment from National Government that any new duties will be fully funded and we look to jointly assess what these new duties are going to be so that Local Government receives an accurate sum to fund these new duties. I have to say that obviously Local Authorities the length and breadth of Scotland are under severe pressure.

You will know from your own localities of some of the really difficult decisions that have had to be made and how do you go about prioritising educational attainment against support for carers? It’s an extremely difficult thing to do. What I would say is that from a CoSLA perspective, we would expect our Local Authorities to begin by looking to ensure that they consult, that they listen to their communities and that they engage with their communities. As I said earlier in terms of support for carers we desperately want carers to be involved in shaping the services that we are going to deliver to them. It will not just simply be a case of Local Authorities spending £88m on carers support. We will be spending significantly in excess of that and would look to continue to prioritise that. I have to say that each of these decisions will be taken by democratically elected politicians within your community and they won’t all come to the same conclusion. They will make different decisions, but we would hope there would be consistency in community engagement, in engaging with the local population, so that the decisions they make are the best decisions for their locality and their communities.

Ruth Wishart I think what the questioner was getting at though, if you get specific resources in respect of new carers obligations, and these are specific resources, that these will be ring fenced and won’t disappear into other pots regardless of the pressure on the other pots.

Peter Johnston Well I think the point I would make on that is that whatever sum of money the Government passes on to Local Authorities in respect of carers, Local Authorities will be spending that sum, plus looking to deliver social care and support for carers and support for everyone else in our communities. There isn’t a mechanism that we have for ring-fencing.

One of the first and from a Local Government perspective one of the best things that the National Government did, was remove ring-fencing and allow Local Authorities to have the flexibility to make their decisions based on an accurate assessment of local need and local priorities. I wouldn’t want to see us go back to the bad old days, where we had a specific sum of money that must be spent for a priority that was determined nationally. I think that leads to inefficiency, leads to bad decisions and leads to poor use of resources.

Ruth Wishart I wonder if you would just like to comment quickly on that Elaine.

Elaine Torrance I think there are concerns around resourcing of the Bill as set out in the Health and Sport Committee Report. I think there are two elements for me. There’s the funding which, I think, we would need that funding to clearly fulfil the duties of the legislation, and so if we are incumbent in doing that, we need the money to do that properly. The second issue is the broader resourcing around the staffing implications, if we broaden out eligibility for assessment, although we would be delighted to do so.

We’ve already got pressure on social workers to complete assessments on the current individuals that we’re working with who are quite high tariff. So we need to really, as this comes into fruition we need to be really thinking through how we are going to do this together so that we don’t end up with more waiting lists or other challenges because that actually defeats the objective. So perhaps we need to be thinking of new innovative ways of doing this together to make it work. But clearly the broader resourcing as well as the finances, I think, are things we need to be working together to get right.

Ruth Wishart We’re going for the next question which is from Lynn Stevenson...
**Q4 QUESTION 4 LYNNE STEVENSON**

“Thank you. The workshop I sat on was Improving Carers Health and Wellbeing and our question to the panel would be – is carers health and wellbeing a public health concern and what plans do each of you have to address this?”

**Miles Mack**
Thanks very much. I think you’re right, I think one of the people in Scotland I understand are carers, and I understand that they contribute a huge amount to the Health and Social Care Services - an estimated £10b each year so we’d be crazy to take this for granted. The first thing we’ve done is the carers and young carers resource pack that we’ve provided for GPs and we are very grateful for our parent/patient group for producing that. We do have a carers register. I’m well aware that it’s pretty scanty and I’m well aware that GPs were slightly arm-twisted into producing this, and I’m not sure if it’s necessarily delivering exactly what we should do and I’m hoping that we can do better in the future. The existing contracts the GPs are already working to is to take into account carers with mental health care plans, structured care plans and diabetes, care planning in dementia and a wider area of anticipatory care planning more generally, and finally some palliative care situations. I think this is the contract that we are moving away from and the Cabinet Secretary for Health announced last Thursday that these very markers will be phased out within two years. That leaves a challenge as to how we make sure that these important areas of governance and quality are attended to. My colleague is striving to bring practices together to work in clusters, to work to a plan of quality which is about values based. And I’m sure part of that will be patient centred and also be shared care type way of working.

**Elaine Torrance**
It does and I hope to see, and I’m sure we will see with integration we are working more closely together. People will be frustrated at times by the fact that there’s lots of different people coming over peoples doorsteps and if we could get better at joining together having more lead professionals, having better single assessments rather than duplicated assessments - all of those can actually make better use of our resources in relation to the previous question. Clearly, I think, there’s also tasks to do around working with communities and sometimes I think support for carers isn’t actually around putting services in, it’s sometimes being able to get that emotional support – talking to other carers, going to carer support groups and being put in touch with people and getting the right information and advice. We’ve got a lot of work to do and I think the work around localities in terms of integration can help us with this. This is where we’re going to be talking to localities about what services are in their area and what do they need, but also about what can the communities offer and work alongside us to provide supporting the broader ways. I think in my local community the churches do a really good job for the people who are interested in that.

**Ruth Wishart**
Elaine a lot of this lies at the door of integrated Health and Social Work planning doesn’t it?

People will be frustrated at times by the fact that there’s lots of different people coming over peoples doorsteps and if we could get better at joining that together having more lead professionals, having better single assessments rather than duplicated assessments - all of those can actually make better use of our resources.

**Jamie Hepburn**
Yes, not just with specific reference to this Government’s policy with carers I should say. I think across the board it will be very important for us for a variety of reasons. The changing demographic population, the nature of public finances, but also I think you get better outcomes for the individual through that preventative approach.

**Peter Johnston**
Yes just briefly. I think my colleagues have covered it but I think the straight forward answer to the question is yes, it has to be and then we move on. I think from a CoSLA perspective, as I’ve said before, looking to empower carers to shape the services they’re getting is very important because that’s the bedrock and we can then move on. We’ve already touched on support for carers in employment and education. I think that’s equally critical to maintaining health and wellbeing but likewise comments from colleagues in respect of the new integrated health and care services. I think what we are talking about fundamentally is shifting the balance of care from the acute sector into the community, and carers are going to play an absolute vital part in making sure that this journey is completed successfully and delivers better outcomes for everyone involved be it the carers, the cared for or our communities. So I think there are challenges ahead but I think carers are going to have an absolute pivotal role in making sure that we do reach the better outcomes that we aspire to, for everyone in our community, through health and care integration.

**Ruth Wishart**
I think this is going to be the last question ladies and gentlemen because of the time factor. It’s from Zahira Hassan.
“Hello and thank you. Our group was talking about improving opportunities for carers and education and training, and our question to you is — how can the Scottish Government help carers to overcome barriers to accessing sustainable education and reaching their potential?”

Ruth Wishart
Thank you, Jamie, a big part of that is making sure they don’t lose their education allowance because of their caring responsibilities.

Jamie Hepburn
Yes, and I eluded to that as being important for the Government as well and I reiterate: the then Minister for Public Health and the Education Minister wrote out to all Education Authorities to remind them of their responsibility to adopt a more flexible attitude to carers. And I was very privileged to go along to the Young Carers Festival recently and some of the young carers there were saying that isn’t always happening which is very disappointing indeed. We need to reflect on that and emphasise the fact that someone there will have responsibility for the Young Carers Statement, I think that will improve things. We are also aware there are sensitivities involved there because some young carers are telling us they may not want their named person to know, so we’re having to reflect on that as we proceed with the Bill. But I think, certainly it would be my hope and expectation, that, that would improve things and the named person would become more aware of the likelihood that there are other young carers out there who may require a bit more support. Beyond that, we are already doing things such as funding the College Development Network to try and develop the Further Education Workforce, to better identify and support carers in colleges. So I’m aware there’s a lot of work to do here to ensure that everybody is engaged in this debate and we take it up a level, and not just to integrated joint boards, but up to Corporate Managements Teams and to the Community Planning Partnerships across Scotland so that we can get support for this agenda together.

Elaine Torrance
Absolutely. So the point I was going to make was we’ve got Health and Social Care integration which is really important, but actually I think there’s a real role of community planning partnerships where we’re bringing together broader partners around housing and all sorts of Skills Development Scotland. All of these bodies together so that we can plan a whole range of services together, not just this particular issue. So I think whilst Health and Social Care integration can deliver something, we’ve got to look broader than this in schools, in colleges with community work and community colleagues. So I think there’s a lot of work to do here to ensure that what we’re doing in this debate and we take it up a level, and not just to integrated joint boards, but up to Corporate Managements Teams and to the Community Planning Partnerships across Scotland so that we can get support for this agenda together.

Peter Johnson
I agree with everything that Elaine has said. We start from the premise of Local Government that carers should not be disadvantaged because they’re carers. And clearly someone who is going to be disadvantaged by losing the ability to reach their educational potential, that’s just not acceptable and we have to do everything possible to make sure that doesn’t happen, and that carers have flexibility in terms of how we deliver education right across the spectrum and across an age group. You’ll know better than I the age of carers can vary dramatically, but a number of them are still in full time education and require our support.

Carer Question (name not audible)
It’s very important, as I’m a mature student and I failed my PhD. I was very ill. I didn’t get support at all from my University and I had to fight. I did mention Nicola’s name before the elections last year and it seemed to do the trick and I’m hoping that my selfie today will further help people like me, mature students. I think we really need something like a dementia strategy to deal with carers.

Miles Mack
One of the privileges of my job is the long term relationships that I build up with my patients and I have been a GP in Dingwall for 23 years now. There’s a young girl who I was well aware had a significant carer role as a young girl going through school and it’s been a delight to follow her through her time to actually having a family herself now. So, I think it’s something about not just being experts in the disease that patients have, but also becoming experts in the patient that has the disease and I hope that at the best, general practice can provide that knowledge and longitudinal care but more than that, we struggle to provide any more than that.

Jamie Hepburn
Yes sorry it probably was rather remiss of me not to. It’s very remiss of me in fact because I was at an event yesterday in Cumbernauld speaking to adult learners, so I should have probably focussed on that a little as well, my apologies. The same point would stand incidentally, just as the Carers Bill implements the Young Carers Statement and implements the Adult Support Plan. So I spoke earlier of that being very person centred so for the individual carer, for them, it is important to be supported around their educational needs, then that Adult Carers Support Plan should be designed to support that. I don’t think you should have to rely on a selfie with the First Minister to get the support you require from university.

So if there’s more that we can do in the formal education environment, just as we’ve sent out that reminder to Education Authorities about flexibility with the Education Maintenance Allowance, then we will look to learn and look to implement that more flexible approach.

Ruth Wishart
Well we really are out of time now and I have to say ladies and gentlemen there are a huge number of people in the room with a huge number of different issues and self-evidently we can’t address all of them properly in the kind of depth that you hope for. Nevertheless, it’s a very difficult thing to put yourself up here and just be in the firing line, literally in the firing line, for things that you don’t know are going to get thrown at you so I ask you to join me in thanking our panelists.
WORLD CAFÉ

Following the showing of two videos about the Healthier and Fairer national conversations, there was an introduction of the purpose of the afternoon which was to explore in a series of conversations on what matters most to carers for a fairer and healthier Scotland.

Two groups of 4 or 5 people were arranged around the edge of each table. People were asked to hold conversations in two rounds, each of approximately 10 minutes duration with the big question “As people and carers what really matters for a fairer and healthier Scotland?”

This sparked a wide ranging conversation amongst participants.

The Parliament identified a series of ‘top points’ per table which were themed as follows:

1. Connection to the wider community
2. Caring for carers
3. Equality and fairness of access to services
4. Joined up planning and better information
The second round of conversation was then introduced where participants were asked to consider the question “How might it be possible for us together, as carers, those being cared for, and society, make progress towards fairness and health?” Again there was a healthy round of conversation.

The Parliament identified a series of ‘top points’ per table which were themed as follows:

1. Traditional community values – seeing the assets
2. Campaigning and lobbying
3. Information and awareness
4. Better service co-ordination

The additional comments provide a full transcript of what was self assessed by the Carers’ Parliament as significant information sitting under these themes. The top points, themes, flip charts used during the conversations and comments have also been fed into the wider “Creating a Fairer Scotland” conversation.

Find out more at: http://www.gov.scot/Topics/People/fairerscotland

WORLD CAFÉ

How might it be possible for us together, as carers, those being cared for, and society, make progress towards fairness and health?

1. The need for listening was mentioned as a theme in 11 tables
2. This was supported by 3 other tables where the term recognition was mentioned
3. The requirement for respite was mentioned at 6 tables
4. The importance of access to flexible working was recorded at 5 tables
5. Practical suggestions to support this included free gym membership, preservation and promotion of green space as an alternative to the gym. 3 tables noted the need to make exercise more accessible, and another 3 noted the importance of supporting the mental and emotional well being of carers
6. A strong theme in the discussions was the encouragement to carers to ‘come out’ and be responsible for themselves and help normalise caring (4 tables) and to imbue dignity and respect for caring activity (6 tables)
7. One suggestion was that carers have a mentor

WORLD CAFÉ: TOP POINTS

1. CARING FOR CARERS

   - The need for listening was mentioned as a theme in 11 tables
   - This was supported by 3 other tables where the term recognition was mentioned
   - The requirement for respite was mentioned at 6 tables
   - The importance of access to flexible working was recorded at 5 tables
   - Practical suggestions to support this included free gym membership, preservation and promotion of green space as an alternative to the gym. 3 tables noted the need to make exercise more accessible, and another 3 noted the importance of supporting the mental and emotional well being of carers
   - A strong theme in the discussions was the encouragement to carers to ‘come out’ and be responsible for themselves and help normalise caring (4 tables) and to imbue dignity and respect for caring activity (6 tables)
   - One suggestion was that carers have a mentor

2. THE NEED FOR EDUCATION ABOUT CARERS

   - There were some practical suggestions to normalise the concept of caring such as:
     - Embedding a carer’s story in a TV drama or soap
     - A social media campaign
     - Having a module in the Scottish Personal and Social Education curriculum on caring
     - Having carers champions in schools and colleges
     - Giving a carer’s allowance rather like an individual learning account
     - Extending the principles of GIRFEC to a higher age
     - Promoting the economic argument about the contribution carers make (2 tables)

   - There were comments suggesting there should be a more nuanced understanding of the concept of a carer, an acknowledgement of different needs at different stages and at different ages, and 5 tables noted that there is still stigma associated with being a carer. This followed up the high level observation already reported that everyone has the potential to become a carer.

   - There were also some individual references to the approach to caring, the significance of a carer being able to tell a story, the importance of not raising expectations, the need for support that is timely, the fact that many carers are already doing these things for themselves, the acknowledgement that some carers simply cannot be called on to do yet more (from two of the tables) and the need to have confidence and seek training in, for example, assertiveness (from one of the tables) and presentation skills (from two of the tables) and three tables noted the risk of a gap between what is said and the reality of the carer’s experience.
THEME 1: CONNECTION TO THE WIDER COMMUNITY
- Developing #happy communities
- Local community developments need to be properly funded, supported and sustainable
- Health and wellbeing clinics for carers
- Support for local community-led activities, groups and services as promoting health and wellbeing which will include carers
- GP accessibility and locations important - different experiences in different areas
- A quicker diagnosis
- Forcing local authorities to ensure a high standard of services for carers and the cared-for

THEME 2: CARING FOR CARERS
- Need support for the carer – the carer as an individual and their specific needs
- Support and clear information
- Once a carer information on how to access support across all domains of wellbeing as well as benefits
- Well informed confident carers!
- Who cares for and guides the carer?

THEME 3: EQUALITY AND FAIRNESS OF ACCESS TO SERVICES
- More equality in quality of life issues
- We need to be realistic – the Scottish Government needs to identify how it can achieve better support for carers
- Adequate standard of living for all citizens
- Healthier eating at cheaper costs
- Unfairness of charging those on benefits for social and personal care at discretion of local authorities
- Fair, simple and just benefits for carers
- Access to all types of health support and advice, using all types of technology to cover moral and urban areas
- A Scotland-wide department and minister for carers
- Importance of appropriate advocates
- To have professionals who are knowledgeable about carers' needs!
- Fairer Scotland would be where all can access systems/services to be able to create the life 'outcomes' they want - then create the support to make it happen. NB do ordinary families talk in the language of 'outcomes'?
- Quality of opportunities and access to services
- Support for young adult carers 18–29 years
- Equality of access to health services – more GPs and social workers and more care workers
- Equality across Scotland for carers support including respite, listening and resources
- Consistency and consistent individual assessment of needs across all needs in Scotland
- An information support line for carers
- Empathy, compassion and values in recruitment
- Prevent social isolation
- (There is) a lack of communication: important to keep carers in the loop

THEME 4: JOINED UP PLANNING AND BETTER INFORMATION
- Remove responsibility for carers from the DWP to the Integrated Joint Boards – integrated health and social care can offer more targeted support than carers allowance
- Accessibility, availability, affordable and affordable respite
- A carer contact within integrated services
- Too much crisis management in mental health – we need a plan
- Need for planned funded provision from health and social care – not organisations like churches
- Respect not pity
- Better signposting to information
- Mental health services need to be preventative appropriate and accessible

- Better training and understanding of needs
- A need for respite/short breaks for carers
- Consistency – consistent support and information across all areas of Scotland; e.g. carers' pathways and emergency planning
- Information support line for all carers

VALUES AND RESPECT FOR CAREGIVERS
- Values and respect for carers - I am a person, don't judge us!
- There is an imbalance between the people who care for people with a disability versus those who deal with substance misuse
- Person centred approach
- Scottish Government media campaign to highlight and educate the public of the impacts (loss/opportunities) of caring and reduce stigma
- Carers to be treated as an expert: listened to and respecting
- At the end of the day a carer knows what they need!
- Positive language and profile in society
- Don't make promises you can't keep. Rhetoric into reality
- Tick...tock...tick...tock... Don't let life fly by - grab it!
- Social acceptance and awareness of carers and their needs – including those of the cared-for person
- Prejudice against carers – listen to us! Listen to me! Help me!
- Service providers to listening and act positively
- Eliminate apathy

WIDER COMMUNITY

THEME: CARING FOR CARERS
THEME 1: TRADITIONAL COMMUNITY VALUES – SEEING THE ASSETS

- Community spirit
- Responsibility and action for all of us to identify carers in a caring society
- Recreate a society
- Educate children and community to support one another – intergenerational work!
- Raising awareness and encouraging dignity and respect for carers
- Show our support and show support for carers publicly
- Care for carers
- Strength in numbers!

THEME 2: CAMPAIGNING AND LOBBYING

- Have a choir of carers for a louder voice
- A PR/media campaign – we have stories that must be heard. Raise awareness through media – radio/TV/news – tell your stories! Carers Scotland and Carers Trust Scotland – putting forward publicity campaign (TV/ radio/local cinema adverts) highlighting carers issues
- Campaign together
- Breakdown barriers between carers and disabled peoples’ groups
- Drip feed positive carer messages – go viral! Using social media to get the message out
- A carers Christmas single
- Flash mob – this has been done in Germany
- Form a union
- Lobby for carers champion in every local authority
- TV mini-documentary featuring carers
- Promote the role of carers
- Media campaign to end negative propaganda and stigma for carers/disabled/cared for
- Campaign for more resources to support young carers, so their family life is protected
- Use our collective voice for a MP/MSP and department for carers
- Stand for silent carers
- Theme - Identifying carers needs
- Carers need to identify a set of core needs
- Get involved/talk to each other and the decision makers
- Come out as a carer!
- Don’t ask carers to do more – lift their burdens and don’t add to them!
- Be informed of the right to choose how much care to provide – including not to provide care at all
- Healthy minds promote healthier living

THEME 3: INFORMATION AND AWARENESS

- Help spread awareness and acceptances by taking the time to explain what a carer is and the issues facing carers to people who are willing to listen
- Effective communication by all is vital – no jargon!
- Educate the education department – carers and young carers visiting schools/assemblies
- Not everyone is the same – we can promote things in different ways
- Freedom of information
- Sharing of knowledge and support for each other
- Remove barriers and improve communication
- Share best practice
- Awareness and recognition of responsibilities of carers

THEME 4: BETTER SERVICE CO-ORDINATION

- One named contact to support carers through the system
- Easier accessible support from specialist social workers – (Empathy, understanding and positive attitude)
- Create a carers’ charter – for equality across Scotland
- Ensure services needed are available locally
- Commissioning and procurement
- Universal design – shape services to reflect diversity in society
- Groups talking to groups
- Some carers are happy to volunteer to run local groups, activities and services
- Lot of caring groups are doing this already – they have no other choice!
CLOSE

RUTH WISHART:

“Ladies and Gentlemen and global citizens of the World Café, thank you very much for your attendance and your attention. I hope you’ve had a day that was stimulating and informative.

I know that there’s a lot that we haven’t covered, but we have covered a lot that might not happen in your own backyard because of the opportunity to come and to network and to meet new friends and to greet old friends.

For me, it’s always one of the best things I do all year and I’m very grateful to you for making it such an inspiring day for me and hopefully for yourselves and I hope to see you all again. Safe home.”

Simon Hodgson

Good afternoon everybody can I just, before Ruth leaves the building, can I just say a special vote of thanks for her today.

This is the third time she has chaired the Carers Parliament, so if you could just join me in thanking her.
EVALUATION

Following the event, Carers Scotland contacted all those who attended the Carers Parliament. Of the 146 carers who attended, 53% responded to this survey.

The Sessions

MORNING SESSION

92% rated the overall morning sessions as either good or excellent.

91% rated the carer interview as either good or excellent.

85% rated the First Minister speech as either good or excellent.

80% rated the themed discussions as either good or excellent.

70% thought time allotted was about right but a quarter said it was too short.

AFTERNOON SESSION

57% rated the overall afternoon sessions as either good or excellent.

56% rated the Q & A Panel as either good or excellent.

57% rated the World Café as either good or excellent.

Chairing, Venue, Catering and Media

100% rated the chairing by Ruth Wishart as either good or excellent.

94% rated the catering as either good or excellent.

25% rated the venue as either good or excellent.

Only 25% had seen any media about the event.

Detailed Feedback

How respondents rated each of the following aspects of the Carers Parliament:

- Room for improvement
- Average
- Good
- Excellent

Chairing: 14% for room for improvement, 86% good, 4% excellent

Venue: 10% for room for improvement, 65% good, 48% excellent

Carer Interview: 12% for room for improvement, 44% good, 48% excellent

First Minister Speech: 17% for room for improvement, 65% good, 33% excellent

Themed Discussions: 10% for room for improvement, 66% good, 35% excellent

Q & A Panel: 10% for room for improvement, 59% good, 26% excellent

World Cafe: 6% for room for improvement, 37% good, 32% excellent

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Carers Parliament 2015 Report
Evaluation & Care Profiles
COMMENTS FROM CARERS

This section contains just some of the feedback from carers which not only welcomes the Carers Parliament but also makes suggestions for improvements, which will assist in planning the next event.

“It’s always a privilege to attend with wonderful & passionate carers attending. A Facebook page with the delegates would be good to keep in touch and help and support each other and discuss in more detail about our day. Thank you. A privilege to attend!”

“I would definitely like to attend next year’s Parliament. I feel it would be better if more time was allowed for “carers questions” and answers to the questions. This would be more beneficial to most carers than joining in a world discussion which really did not go anywhere.”

“Yes, thanks for the opportunity to participate – it would have been more constructive to have a Q&A with FM and the minister only, rather than the GP, the CoSLA and social work reps. I would like to come again.”

“Age Scotland would definitely like to attend future Carers Parliament as the issues raised are useful for our policy teams agenda.”

“Yes, I would like to attend future Carers Parliaments. Thought should be given to location, providing sufficient catering table seating for us old ones and ease of access from all transport hubs in the city.”

“It might be useful to send out some questions beforehand so the people can have something prepared and not put on the spot to comment. A whiteboard where any delegate can put up a comment relevant to caring...ie I’m currently following the inquest of a death of a young man in care in Oxford and would have liked to raise awareness of the #LBInquest.”

“More media coverage would help. I have now been to all of the Carers Parliaments and feel so privileged to have done so. But probably I ought not to apply for next year to give someone else the opportunity. More publicity through local carers centres should be promoted to spread the word. More regional events might help to let carers participate in smaller gatherings which might be less daunting for those who would be too shy to say anything in a bigger group. I must say that to participate in the Carers Parliament is such a pleasure and to meet with carers from all the airts is so interesting and stimulating - being with a group of people who know what it is really like to be a carer. It is a chance to learn from each other. I like the idea of Q&A with specific ministers - but not too many at a time! - so that questions could be sent in advance and with opportunity to interact if you wanted to question the answer or get further elucidation.”

“Yes would attend. Would hope to help make a difference and asked more about my struggles so I’m heard and policies can adapt.”

“Yes, thanks for the opportunity to participate – it would have been more constructive to have a Q&A with FM and the minister only, rather than the GP, the CoSLA and social work reps. I would like to come again.”

“I would definitely like to attend Carers Parliament in the future. Although I think I’m quite motivated to improve life and work hard to get what my daughter needs, not all carers have this ability and it’s important to recognise this. However, on the flip side, I continually meet people in life who want everything done for them (not just carers) and it’s important for them to know that they need to work to achieve their desired outcomes. This also ties in with commitments around integration.”

“I would be very interested in attending a future Carers Parliament. Q&A with specific ministers would be useful. Attendance by more local MSPs to raise awareness and take local feedback to specific ministers so that we feel both our local and national issues are being addressed. Newsletters to keep carers informed of issues, progress, support etc. More use of technology to keep carers informed as it may be difficult to attend meetings, local events etc especially if you are a working carer.”

“Yes would be very interested in coming back. Was great. As an isolated carer from a rural area it gave me a real lift.”

“Yes would attend. Would hope to help make a difference and asked more about my struggles so I’m heard and policies can adapt.”

“I would definitely like to attend Carers Parliament in the future. Although I think I’m quite motivated to improve life and work hard to get what my daughter needs, not all carers have this ability and it’s important to recognise this. However, on the flip side, I continually meet people in life who want everything done for them (not just carers) and it’s important for them to know that they need to work to achieve their desired outcomes. This also ties in with commitments around integration.”

“I would like to attend a future Carers Parliament. Newsletters would interest N.A. Carers. Thank you.”
The Carers Parliament is a good organisation and I see improvements each year I have attended. Yes I would attend future Parliaments. The feedback to my Carers Centre is vital to keep them informed as to what is happening. I was disappointed there was no press coverage following the Parliament. I look forward to receiving news of the outcome and if anything has been proposed to put before the Scottish Parliament. Local events and newsletters would be a good idea with publicity. Q&A with ministers good but this year there was no commitments.

“I would be very interested in attending future Carers Parliaments; from a personal point of view Edinburgh is a good venue. Maybe having smaller, local events to gather carers views on the issues to be highlighted before the actual Parliament would be a good idea, then a ‘representative’ could take their local group’s issues and questions forward.”

“I would like to see young adult carers better represented and table discussions specifically for us and for the panel to be asked questions that the audience could volunteer instead of having to agree one as a group the cafe I felt could of been put to better use as we could have given each table a question about health and see how that table could solve that problem.”

“I was quite disappointed that there was no press coverage of Carers Parliament this year. I would have liked to see the Parliament more local events to gather carers views on the issues to be highlighted before the actual Parliament would be a good idea, then a ‘representative’ could take their local group’s issues and questions forward.”

“After attending the Carers Parliament this year I would definitely like to be considered for future events, I feel I gained a lot of useful knowledge and some confidence that I am not the only person in my situation. I think that by holding more local events will help increase other people’s awareness of the vast amount of carers there are.”

“I think it may be appropriate to have some break out areas where people can just chat about their caring situation at the next Carers Parliament. If people have not had the opportunity to talk before then often the table discussion can be a chance for them to blow of some steam. This can then detract from the remit of the table discussion. Break out areas could perhaps be facilitated by carer support workers, with the discussion centred around how do you look after yourself. Reading my comments back it may look like a bit of a moan, but I can honestly say I did thoroughly enjoy my day. Thank you.”

“I see the Carers Parliament being valuable for carers, service providers and government bodies. They help to inform and influence these bodies about carers day to day issues and concerns as well as allowing us to feed more innovative ideas. I would attend another parliament, but I am conscious of not doing this at the exclusion of new potential carers. One really good thing we had this year was the attendance of Scottish Government officials responsible for drafting the Carers Bill. The booklet stall in the entrance hall was rather disappointing. Would it be possible to host a number of manned stalls instead, especially those promoting innovative or new ways of caring. It would be great if we could hold a carers parliament on the western side of the country, to even up the political draw of Edinburgh.”

“The Parliament is a brilliant innovation. It might be good (if possible within resources) to feed back on issues raised; eg the issue around SDS in Shetland raised by a delegate in Group 1 in the morning.”

“A Q&A session with the First Minister if she/he were to attend future Parliaments would be a positive improvement. More time allowed for questions to the panel would make for a more engaging process, having said that this year Panel not including Ruth Wishart were a pretty dull bunch in my humble opinion.”

“I really enjoyed the day and would be very happy to attend future Carers Parliaments. I assume we get copies of the findings of the Parliament. Are these also sent to Local Authorities and MSPs? It would have been helpful to have the constituency shown beside the delegate names. It was helpful to know in advance what the topics would be but it would have been useful to have a bit more information about the workshop topics in advance and also which workshop we would be in. Perhaps local and national politicians could be encouraged to have local mini parliaments on issues which affect carers in their area.”

“I would be very interested in attending another Carers Parliament. I would have liked to see the panel sessions extended with an opportunity for carers to respond. It was the first time that I have attended the Parliament and I found it very informative and enjoyable.”
I would like to see young adult carers better represented and table discussions specifically for us and for the panel to be asked questions that the audience could volunteer instead of having to agree one as a group the cafe I felt could of been put to better use as we could have given each table a question about health and see how that table could solve that problem.

"My first Carers Parliament was a worthwhile opportunity and I would be very keen to attend again should the opportunity arise. I feel very strongly that carers have to be actively involved and willing to share experiences both positive and negative to help others. Previously my caring role meant that I was unable to be active in campaigning for people with dementia. I live on Skye and despite repeated requests for forward planning to meet long term residential care needs when the crisis happened due to lack of local support resources, my partner was required to move to Glasgow (a 460 mile round trip from home) as there was no provision in the Highlands. As I am regularly down in Glasgow I was able to link in the event a visit which meant I did not need to claim any expenses, but was able to represent the electoral area. Thank you for the opportunity of attending this years event and I will be doing a small report to submit to NDCAN in the near future."

"I was very honored to have had the opportunity to attend. I am grateful for the help & assistance I received with accommodation & booking. As a carer to have time to yourself was bliss. Hotel was very comfortable. I would be interested in attending a future Carers Parliament."

"I really enjoyed the experience at the Carers Parliament. I would like have the opportunity to come back and do it again."

"I would like to attend future Carers Parliaments if possible. I think something that would be of interest would be a discussion on housing. Housing for people with special needs and housing in general for people who are getting older and maybe require some form of care. I believe that all new private housing developments, should have a proportion of bungalows built, with wet rooms etc, so future caring needs are already in place."

"Yes I would attend another Carers Parliament. It would be better if it was over a couple of days to give us more time for seminars, discussions and networking but I realise a lot of carers wouldn’t be able to spare this time away from their caring roles."

"Yes I would be interested in attending next year’s Carers parliament but also any follow up events during the year."

"I would be very interested in attending next year’s Carers Parliament. Maybe by then I would have more confidence to offer a contribution. Now I am keen to follow progress of the Carers Bill. Lunchtime networking was useful for me, and I think about the right length of time."

"I really enjoyed the day and I am going to give feedback to different organisations throughout the Western Isles about the event."

"I would be interested in attending again and other events, but it would obviously depend on me being able to get carer for the event. I would like to be able to contribute and voice my views too without having to attend. Ie like I saw places were available at a women only event in Glasgow and I contacted the event organiser to ask that the issue of women carers pensions be mooted as that is of interest to me! A carers centre in North East Fifes! Some pressure on local and Scottish Government to make planned respite breaks available to all in all areas even those who need nursing care and an ambulance to get there."

"I would be interested in attending future Parliaments perhaps not next year. It would be good to have more info re workshops in advance. I mistook Equality as Carer with professionals not gender, race, LGBT or Transgender and religious equality. It would also be good to have the chance of preparing a few questions for the panel and a pen portrait of each panel member some weeks beforehand."

"I enjoyed the day and I am going to give feedback to different organisations throughout the Western Isles about the event."

Thank you to everyone involved in arranging, coordinating and organising. A great venue, chair, programme etc. Well done everyone - you did carers proud - again.

"Yes I would very much like to attend the next Carers Parliament. Maybe by then I would have more confidence to offer a contribution. Now I am keen to follow progress of the Carers Bill. Lunchtime networking was useful for me, and I think about the right length of time."

"Too many of the same people attending (including me!) need to also revamp afternoon to be more about inspiration, aspirations, maybe a carer telling a positive story to balance the negative to help others. Previously my caring role meant that I was unable to be active in campaigning for people with dementia. I live on Skye and despite repeated requests for forward planning to meet long term residential care needs when the crisis happened due to lack of local support resources, my partner was required to move to Glasgow (a 460 mile round trip from home) as there was no provision in the Highlands. As I am regularly down in Glasgow I was able to link in the event a visit which meant I did not need to claim any expenses, but was able to represent the electoral area. Thank you for the opportunity of attending this years event and I will be doing a small report to submit to NDCAN in the near future."

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"Yes I would be interested in attending future Carers Parliament and would like to be involved from a carers perspective."

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I would be interested in attending a future carers parliament. Found it very good & certainly got to speak to a lot of interesting people. All seemed a bit rushed over one day .. perhaps 2 days and the ability to attend a couple of workshops.

“I would like to have more 1-1 surgeries with professionals from Health/Social Services/3rd Sector Organisations and ministers to deal with carers issues. And what they can do to help individuals.”

“Yes, I would be interested in attending again (and repeatedly). We need to get Councillors and MSPs involved. We need to be able to count the economic cost of carers having to leave employment (and being unable to get back in again for the predominant age groups caring), and what that means for Scotland’s prosperity. Then multiple and distance caring, young carers unable to access further and higher education and what that means for their future lifelong disadvantage in society. It was lovely to see so many young carers this year - but also heartbreaking. There are also all the issues about Welfare “Reform” and the “care tax” constantly hitting the same people. We need to do things very differently -where people want them to be different of course.”

“Thank you for inviting me. It was an excellent day. A future Carers Parliament should be held in Glasgow as I was speaking to quite a few folk who lived in the West of Scotland.”

PROFILE OF ATTENDEES

The following provides a demographic breakdown of the carers attending the Carers Parliament.

AT A GLANCE

88% carers

74% female

85% heterosexual

12% former carers

26% male

2% gay, 2% lesbian, 1% bisexual, 10% preferred not to say

AGE

23.70% 17 or younger

4.05% 18-20

3.47% 21-29

6.36% 30-39

26.01% 40-49

23.70% 50-59

6.94% 60-69

0% 70-79

0% 80 or older

DISABILITY

35% of delegates said that they had a disability or long term condition.

ETHNICITY

97% of those who attended were of white ethnicity. Of these 79% were Scottish, 12% British, 5% English, 0.6% Welsh, 0.6% Irish, 0.6% Gypsy Traveller and 2% “other” white background.

Of the remaining delegates 2% were Pakistani, Pakistani Scottish, Pakistani British ethnicity and 1% Black, Black Scottish, Black British ethnicity.

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?

<table>
<thead>
<tr>
<th>Number of People</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>74%</td>
</tr>
<tr>
<td>2</td>
<td>13%</td>
</tr>
<tr>
<td>3</td>
<td>3%</td>
</tr>
<tr>
<td>4</td>
<td>0%</td>
</tr>
<tr>
<td>5+</td>
<td>1%</td>
</tr>
</tbody>
</table>

How long have you provided care?

<table>
<thead>
<tr>
<th>Time</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1–4 years</td>
<td>6%</td>
</tr>
<tr>
<td>5–9 years</td>
<td>23%</td>
</tr>
<tr>
<td>10–14 years</td>
<td>20%</td>
</tr>
<tr>
<td>15–19 years</td>
<td>14%</td>
</tr>
<tr>
<td>20+ years</td>
<td>28%</td>
</tr>
</tbody>
</table>

REPRESENTING CARERS ON OTHER GROUPS

Of those who attended,

35% were carers who are carer representatives on local carers strategy groups, 15% on new integrated bodies and 8% on NHS public partnership groups.

Who do you care for?

Tick all that apply

<table>
<thead>
<tr>
<th>Relationship</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent or parent-in-law</td>
<td>34%</td>
</tr>
<tr>
<td>Child over 18</td>
<td>33%</td>
</tr>
<tr>
<td>Child under 18</td>
<td>17%</td>
</tr>
<tr>
<td>Spouse or partner</td>
<td>20%</td>
</tr>
<tr>
<td>Sibling</td>
<td>7%</td>
</tr>
<tr>
<td>Another relative</td>
<td>7%</td>
</tr>
<tr>
<td>Friend or neighbour</td>
<td>3%</td>
</tr>
</tbody>
</table>

What condition do they have?

Tick all that apply

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning disability</td>
<td>50%</td>
</tr>
<tr>
<td>Long term condition</td>
<td>47%</td>
</tr>
<tr>
<td>Physical disability</td>
<td>39%</td>
</tr>
<tr>
<td>Mental ill health</td>
<td>25%</td>
</tr>
<tr>
<td>Dementia</td>
<td>15%</td>
</tr>
<tr>
<td>Frailty due to old age</td>
<td>15%</td>
</tr>
<tr>
<td>Substance or alcohol dependency</td>
<td>4%</td>
</tr>
</tbody>
</table>

Carers Parliament 2015 Report
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.

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