



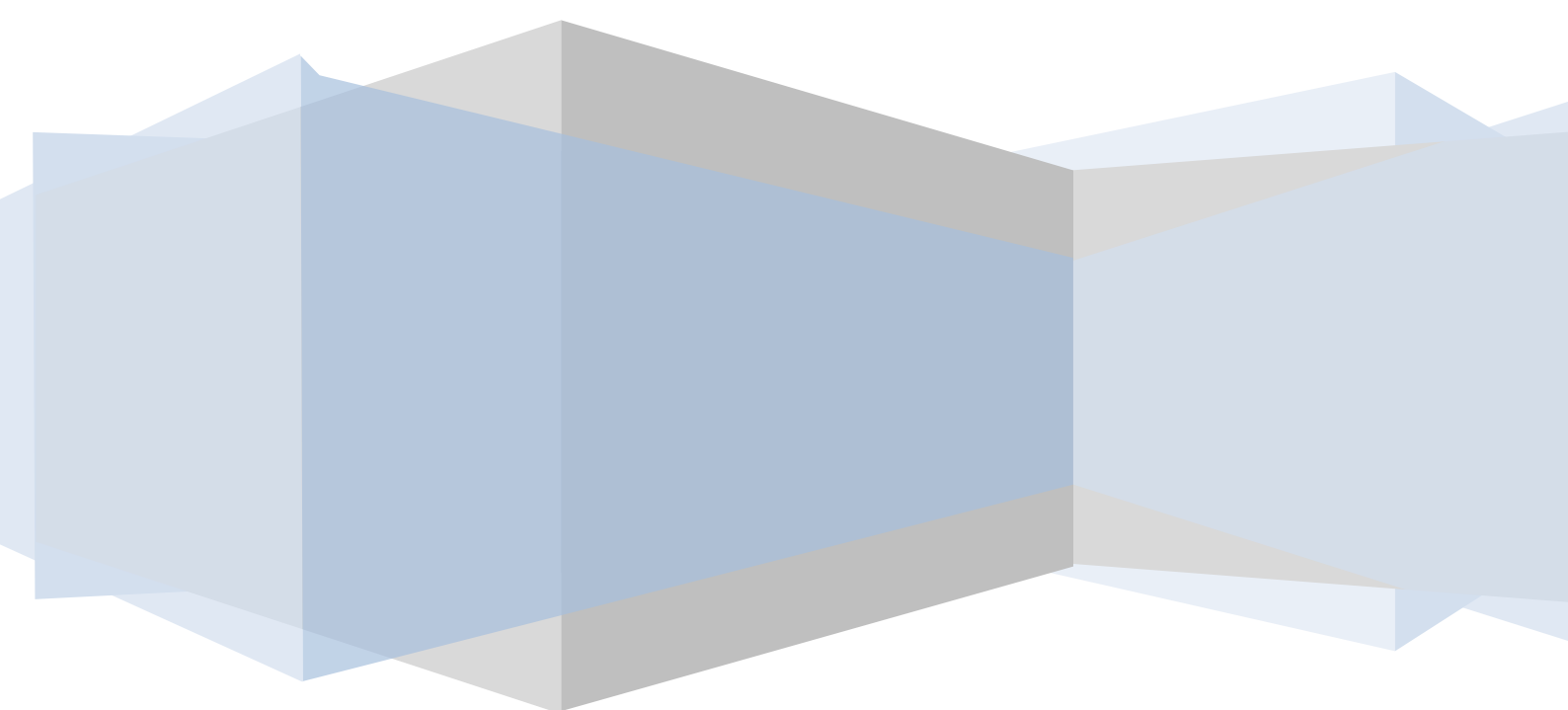
Highland Carers Strategy Development Project

CARERS SURVEY 2020 Summary Report

Jennifer Campbell

Carer Services Development Officer, NHS Highland

November 2020



Background

In summer 2020 a survey was composed by a small working group made up of members of the Carers Improvement Group; to increase awareness of the complex role unpaid carers have and highlight ways to deliver what matters most to people living with a caring role in Highland.

The survey was 'live' on Survey Monkey between 8th September to 13th October 2020 with local carer organisations promoting the survey through newsletters and via social media pages. There were 153 responses to the survey, 147 via Survey Monkey and 6 hard copies.

Survey Objectives

The objectives of the survey were:

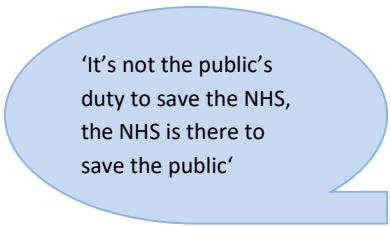
- To help form a partnership between unpaid carers and carer organisations to create the Highland Carer Strategy 2020-2023
- To hear from carers with regards to what type of carer services and resources they wished to see more of moving forward
- To hear personal experiences of caring for carers at home during the Covid pandemic and experiences of caring from someone who had to spend some time in hospital or had been admitted permanently into a care home

The findings from the survey will be used to inform NHS Highland's strategic carers plan and to ensure effective communication between unpaid carers, carer organisations and NHS Highland.

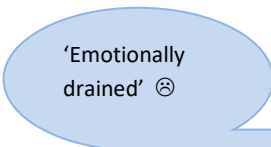
Impact of Covid Pandemic on caring

76% of recipients told us they felt more socially isolated in their caring role during the pandemic and 69% told us they also felt more stressed. We received 46 written comments about carer's experiences of Covid and these included:

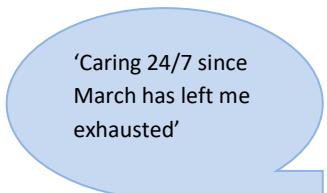
- Concerns about seeing loved ones in a care home or hospital during this time
- Managing caring responsibilities whilst shielding or caring for a loved one who was shielding, this included difficulties with online shopping
- Lack of regular routine, no day care and/or regular respite breaks meant many carers felt alone and anxious.



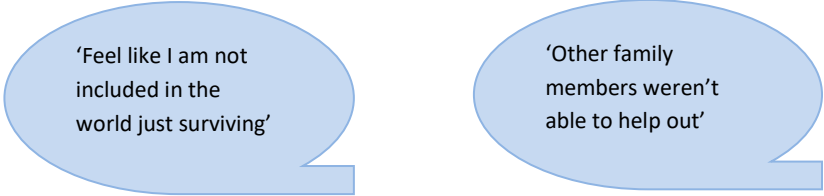
'It's not the public's duty to save the NHS, the NHS is there to save the public'



'Emotionally drained' 😞



'Caring 24/7 since March has left me exhausted'



'Feel like I am not included in the world just surviving'

'Other family members weren't able to help out'

Adult Carer Support Plans

50 respondents told us they had an adult carer support plan but there was no indication of when that took place. Respondents were asked how they felt about the plan and the majority said they found it useful.

It was encouraging to note that many of the respondents commented on how beneficial the process of completing the plan had affected them. Using words such as useful, reassuring and supportive, 15 of the respondents commented explicitly on this aspect. The opportunities to 'think things through' and 'to see my own life better' and 'to plan better' were welcomed.

Having someone to talk to about their situation was also welcomed: *'it was good to have someone to talk to and to help me focus'.....*

Taking the plan as a whole a further 16 respondents commented that the plan had been 'useful' or 'very useful' to them

Only two of those that thought it useful commented that that was because it had resulted in a support package being obtained as a result, although it was not clear if this was for the carer or cared-for person.

That the Carers Support Plan didn't result in additional services was the big source of dissatisfaction and a number of respondents felt that there had been no follow up or that their plan required updating. Two respondents referred to how busy the carer link workers appeared to be and that consequently the service they had received from Connecting Carers was less than satisfactory.

The number of responses to this question is quite small in relation to the actual number of plans carried out so it is not easy to draw many firm conclusions but the responses do give some indications of where the current system could be improved.

Support over the past six months

30% of carers told us they had received grant funding over the past six months that had allowed them to purchase a laptop, tablet or mobile phone and this resource had helped them greatly during lockdown. Telephone support, attending online planned sessions and use of creativity kits had all had a positive outcome for carers leaving them feeling supported and engaged.

Short breaks

We explained to carers that short breaks come in many forms offering a list of possible options with carers suggesting that 'carer friendly holidays (38%) self-help programmes (33%), peer support (26%) personal development programmes (24%) and activity kits (23%) could all offer short break opportunities that would enhance the carers health and wellbeing. We also asked carers to provide us with their own short break ideas and 30 carers responded with some interesting and innovative ideas that included:



What other supports would assist you in your caring role and proposals to move these forward?

The general feedback from this open question suggested that there are solutions that can be put in place to provide better more tailored support for carers. Some of the issues raised can be dealt with quickly and others factored in to the Highland Carers Strategy.

Carers told us the following and this is how we expect to address these issues:

1. Many carers felt that better adult social care/social work involvement including care at home, restarting day care and care home respite was required;
There are plans afoot to develop an e-module on the role of 'unpaid carers as equal partners in care' that should assist NHS Highland staff of the importance of working in partnership with carers
2. Creative use of SDS budgets would help greatly
Work is currently underway with adult social care teams and carer link workers to ensure the SDS Options 1 & 2 are utilised to support carers to develop bespoke short breaks.
3. Information on what is available – held in a central location rather than navigating numerous websites
The Carer section on the NHS Highland website has been updated to ensure all pertinent information is available for carers with links to carer services within Highland and national organisations included

<https://www.nhshighland.scot.nhs.uk/YourHealth/Pages/Carers.aspx>

4. Carers Allowance, lowest benefit of its kind doesn't take into consideration when you care for more than one person
Highland concerns have been fed back to national carer organisations. 75 organisations from across the UK are currently working in partnership to lobby the Westminster Government to immediately raise Carers Allowance
5. Support from other carers would really help
Care organisations continue to offer support to carers that have included development of more informal peer groups via 'What's App' and Facebook groups.

'Someone to be with my husband so I could have a day out'

'Respite – without the social work headache of planning it!'

'A short break to get away from it all'

'Connecting with others'

'Seaside breaks heal the mind'

'Someone to talk to'

Hospital Admissions

66% of respondents told us the person they cared-for had had a hospital admission. The majority said they had been involved in the hospital admission process (81%). However feedback on hospital involvement was mixed with some carers feeling they were not treated as equal partners in care or actively involved in discharge planning, to some carers relaying their hospital experience was exemplary.

A Carer Hospital Link Worker based between Raigmore and New Craigs Hospital was appointed in August 2020 (after the post had been vacant since February '20) and is working alongside hospital representatives to ensure NHS staff have an understanding of their statutory responsibilities within the Carers (Scotland) Act 2016 and that carers are actively involved in planning for hospital discharge. We are also working with the Caithness redesign team to ensure carer support is factored into the redesign plan within Caithness General Hospital

'Listen to carers'

'Provide meal preparation facilities for carers'

'Make sure everything explained to the patient is shared with the carer too'

Move from hospital permanently to a care home

7% of carers told us their loved one had moved from hospital into a care home. Carers found it hard to have to visit and choose a care home for their loved ones particularly during Covid and there was mixed feedback on the communication around the planned moves, this appeared better for moves from community rather than acute hospitals.

We asked recipients how we could work with them as equal partners. The feedback to this question was overwhelming with 59 responses.

We categorised this feedback and here is what they told us:

- Home care can be problematic particularly in remote and rural areas. There can be long delays in assessment (for the cared-for person). A small number of carers had found the social care process confusing. They had not felt respected or treated as 'equal partners' and experienced lengthy delays in response (if any) to phone calls or emails.
- The shift to online support has assisted many carers, meaning that they don't need to plan travel to attend events and can fit the sessions in alongside their caring responsibilities. However there were also concerns that the shift to online engagement meant it was hard for some carers to fully engage (because of their caring responsibilities) and timings of sessions didn't fit with school runs etc. Clearly most carers would welcome face to face contact once again
- Carers Allowance is too low and if caring for more than one person doesn't take into consideration the actual 'caring hours' and stops as soon as carers reach retirement pension age.
- No day care provision at present is having a major impact on carers, caring 24/7 for a loved one is exhausting and draining and as the pandemic continues no clear plans on reinstatement of day care has left many carers at 'breaking point'
- Finding out information for carers can be a real mind field.

'Access to a solicitor would help'

'We are all exhausted caring 24/7 over the last few months and desperately need a break'

'I worry about returning to work full time'

'Connecting Carers have been amazing offering lots of support art this time'

'I'm lucky to be the carer for my sister but don't feel supported at all'

'I am overwhelmed & not able to take on any more'

Recommendations

We really value the time that carers took to complete the survey particularly when many are caring 24/7 single handed at this time. Their open and honest feedback around how we can improve services for carers in Highland will assist us greatly to develop the Highland Carers Strategy. We hope to have addressed many of the issues carers have identified throughout the report and through inclusion in the new strategy in the following ways:

- Use of Self-directed support in a more creative way to permit short breaks particularly whilst previous services are not available
- Support to plan and arrange short break opportunities
- More proactive involvement of carers throughout a cared-for persons whole hospital journey

We want to ensure that there is an effective working partnership between unpaid carers, carer organisations and NHS Highland and therefore plan to share the draft copy of the Highland Carer Strategy 2020-2023 prior to its submission to Highland Health & Social Care Committee for sign off. There will then be opportunities to chat through the content of the strategy via a series of virtual meetings.