



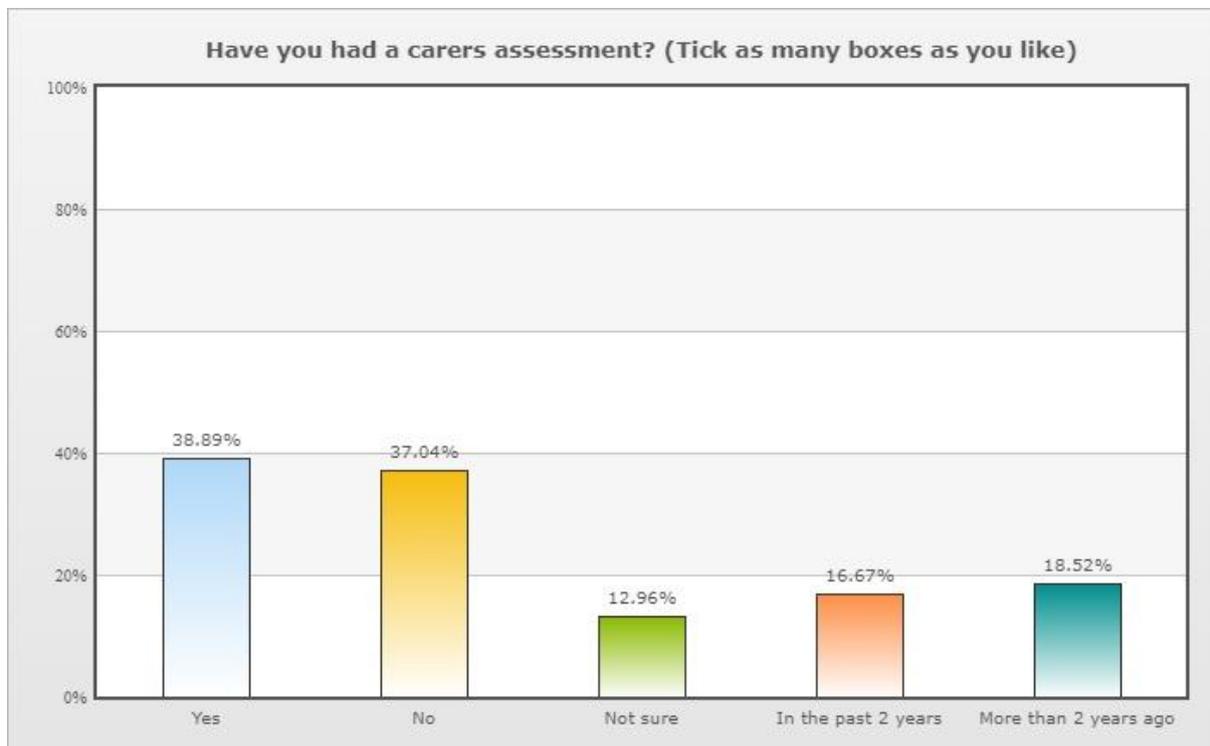
## Interim findings of a survey of carers carried out by Cardiff & the Vale Parents' Federation May 4th 2020

Cardiff & the Vale Parents' Federation contacted its membership to assess how they were managing during the Covid-19 crisis and lockdown. The [survey](#) is currently active and online being promoted via social media, SMS and emails and other online means. This summary of the findings to date outlines some common themes and feedback so far collated.. A full report will be compiled but updated findings will be reported to local authorities in the region to help them prioritise support according to needs

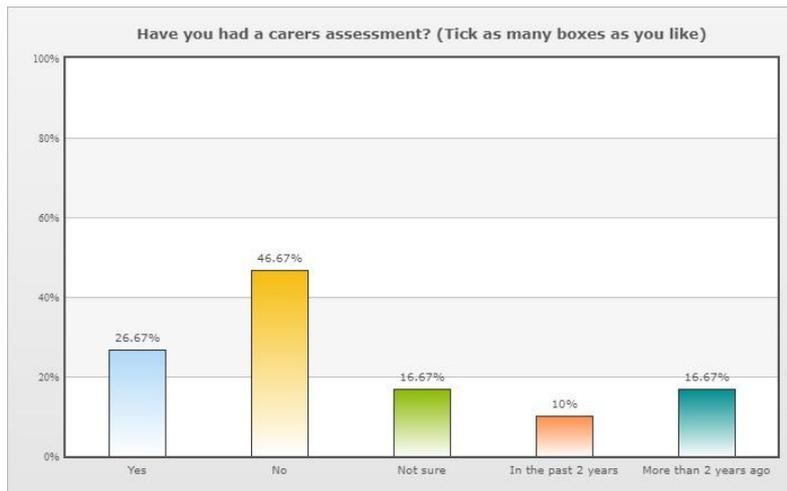
### Where people live

Respondents were from Cardiff (41%) and the Vale of Glamorgan (59%). This does not reflect the split of carers we have as members and would expect Cardiff responses to be closer to 70% so this version of findings are more skewed to the experiences on carers in the Vale of Glamorgan and should be interpreted accordingly

### Carers Assessment



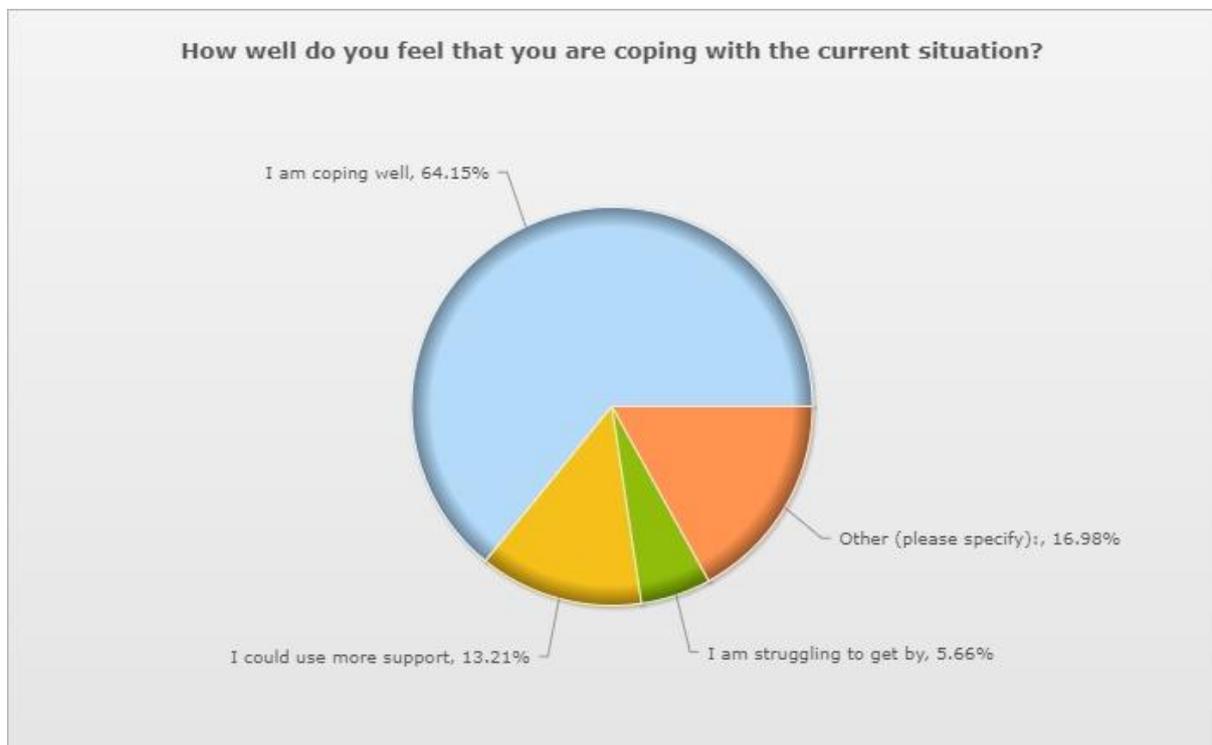
May 4<sup>th</sup> figures

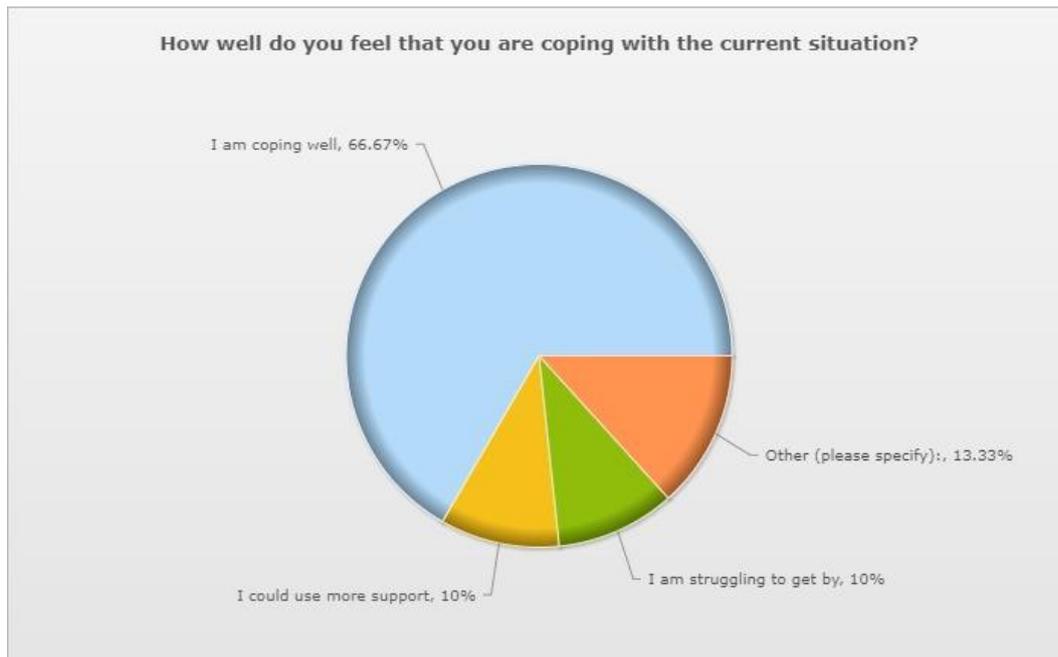


*Findings in April sample*

Approximately 2 in five carers have had a carers assessment and the same number have not. Of those who stated they had just over 50% have not had one in the past 2 years. Around a fifth of the total respondents were not sure if they had been assessed (this may be a result of a joint carers and carers for assessment).

### **Coping with the situation (as a carer)**





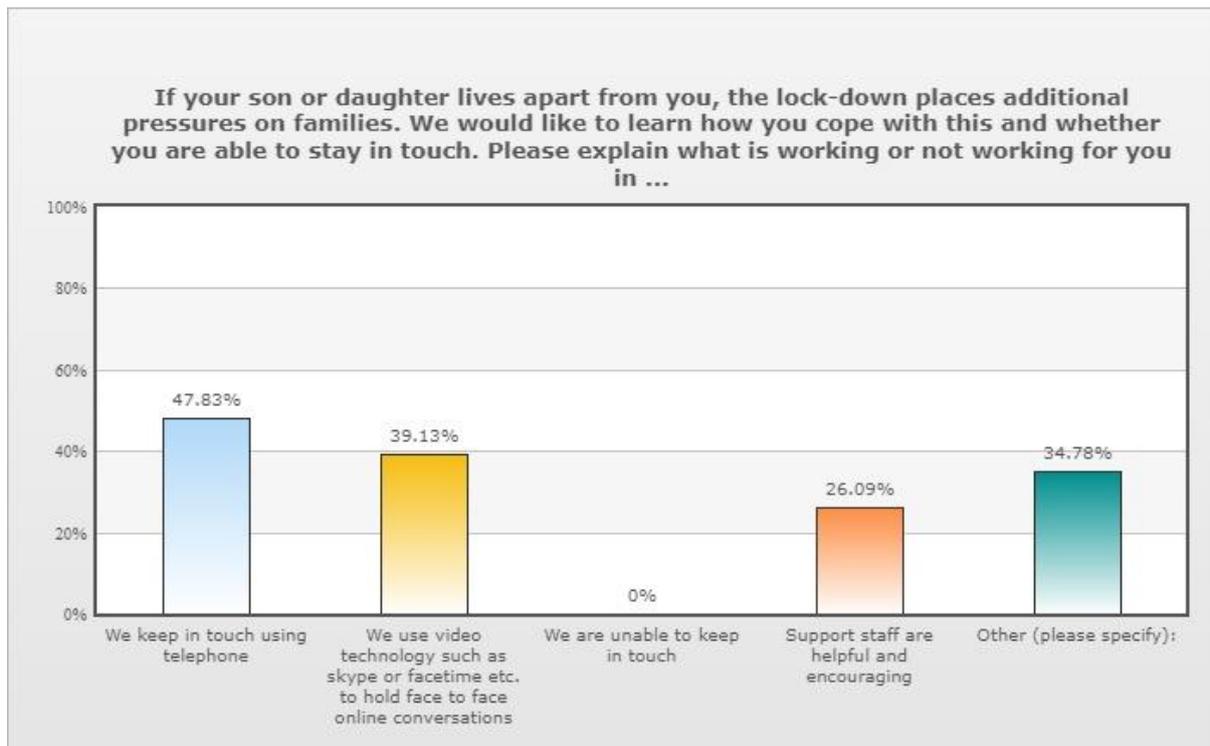
Almost two thirds of carers are still coping fairly well with the external crisis and its challenges, this reflects the earlier April analysis. What is of note is that but. However, a fifth of carers are starting to struggle or need additional support. It must be noted that many of these respondents will not have their relative living with them and where this is the case several report having ups and downs with daily challenges. Quotes such as '*... Good days and bad days, for both myself and my son' ... 'I feel very low then other times feel great, trying to keep my son who has LD and partner who works from home, motivated and happy'*... highlight this.

### **Additional support**

Difficulties in shopping and getting basic provisions has been highlighted by a significant number of carers, lack of support or difficulties with GP surgeries was highlighted by others. Financial issues and carers assessments were flagged up and the benefit of having a good PA or support was stated by several families.

Even where families have a shielding letter getting online priority slots can be a challenge and several parents would like some input from schools to help maintain their child's education. The need for computers and IT equipment (and access to internet) was also highlighted.

## Issues arising for those whose children live away from home

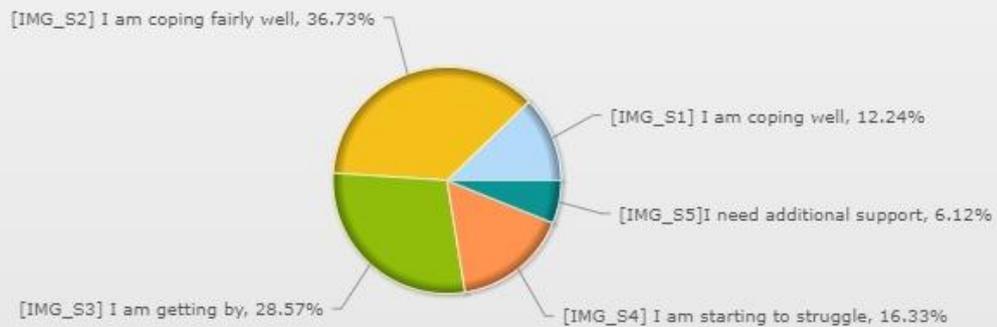


A third of respondents use video or telephone to stay in touch but some have had their child return home. Others are concerned over the safety of their child living in close proximity to others especially if care staff are not practicing safe hygiene

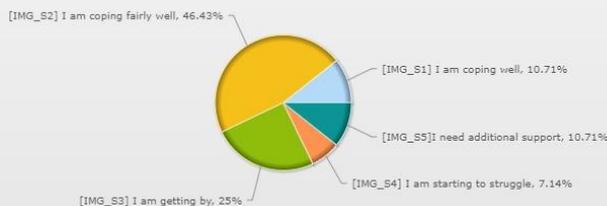
Two thirds report support staff being helpful and nobody reported that they were unable to keep in touch with their loved one.

## Caring for relative in the family home

If you care for your son or daughter at home we would like to know how the lockdown is affecting you. Please share any tips, advice or suggestions you have in the comments box



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Many families that are supporting a relative with the family home during lockdown report coping on the whole but some are facing a great deal of difficulty in some aspects of their daily lives. Since the first summary of findings the numbers of families 'starting to struggle' has more than doubled to over 16% or and those coping 'fairly well' has dropped from over 46% to under 37% .

Some families have found themselves caring for their son or daughter unexpectedly, placing pressure upon themselves. Others lack privacy and try to shield their 'child' from the news to avoid anxiety. Accessing foodstuffs and basics is proving more and more difficult to others, especially where they have no other support to call upon when shopping or getting essential supplies in. For some people their situation is likely going to deteriorate without external support at a time when carers and PA's are in most demand.

### Concerns and fears

These include Financial difficulties, Access to health care, shortage of food, Mental health deterioration and a lack of physical activity taking its toll. For many returning to school will be

difficult and families foresee problems. These are made worse by children missing schooling and catching up with the syllabus.

Several respondents expressed a lack of confidence in authorities/government ability to handle the situation- might rush into returning to 'normal' without sufficient safeguards in place.

As the lockdown has continued an increasing number of respondents highlight concerns over their 'coping mechanisms' failing and their vulnerability if the main carer fell ill themselves. Burn out on the part of the carer was highlighted and the isolation of some was highlighted in one quote, '*... I could die in the house taking care of my daughter and son and no one would know..*'

The extended separation from sons and daughters living in supported accommodation is an increasing concern and source of stress.

### **Positive outcomes arising from the lockdown (and problems)**

Family time, reduction in stress, no school anxiety, more family time and talking to friends, catching up on work and jobs around home, taking stock and putting things in perspective, opportunity to help others through involvement in online support groups, stronger local community and not having to rush all the time.

One carers' quote sums up experiences well... *"It has made me realise what is important. Family Time spent together. Talking and listening to each other. Health, supporting each other. Coming together as a community"...*

Some support agencies have been very supportive to families e.g. Vale Plus (who support young adults with additional learning needs) are keeping in touch with families and sending resources to help occupy them.

Many carers report some degree of positive outcomes arising from the enforced isolation as the following quotes suggest;

*'Everything much more relaxed, slower pace, not usual life pressures and not feeling guilty because I have no choice about it! 😊*

*I take my hat off to the local authority which has taken action which, for our part, has been helpful along with support from Dewis and Parents Federation contact. I'm been really proud to live here seeing how quickly matters are being dealt with. Very thankful!*

*'Wonderful to be able to 'slow down'. Never thought I could cope with this long at home with two children with complex needs and I am coping better than expected. The children appear happier and more relaxed'*

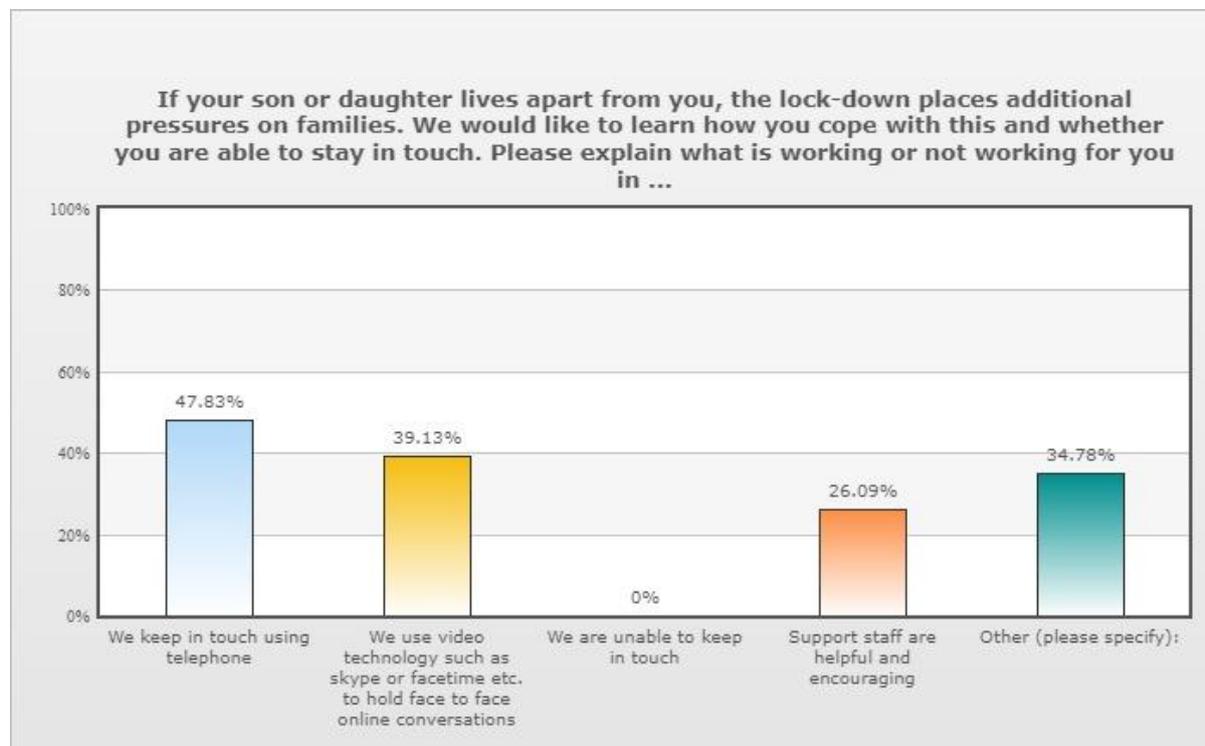
We assume the above are those carers that report being able to cope well but not all carers reported such positive outcomes. Some have found themselves even more isolated while neighbours ignore or overlook them. At best no difference or a continuation of a long struggle to get by. A lack of finance was also highlighted as were concerns that children may not want to return to school or supported living settings after such a long time at home.

Quotes such as those below speak for themselves:

*' No support, No help, Nobody cares'*

*'No difference to us, we have already been alone and isolated for the last 8years. Only difference is, now its a struggle to get deliveries.'*

## Keeping in touch with relatives in supported care settings



Almost half of carers keep in touch using the telephone and two fifths use online technology such as skype etc. Over 40% of respondents say that they find support staff helpful and encouraging. Some carers find that support staff are not as capable with ensuring the use of IT and means to keep in touch and others are keen to have their child return home. Concerns include the state of a relatives mental health in lockdown away from their family, safety and hygiene practices not being adhered to.

### Concerns for the future

A lack of suitable opportunities/services after the lockdown ends

Shortages in staffing and safeguarding issues on return to 'normality'

School issues, especially around future transitions and the need for a 'bedding in' period to ease back into school life. These have been made worse in some situations because of the speed of returning from college or school with little or no planning. The future post the September academic term is becoming a source of stress and uncertainty

Problems arising as children become used to home life routines and reluctant to return to school

Too early a return to 'normal' risks putting people at risk

Caring at home for someone 24/7 in a busy household is placing an increasing pressure on carers and their mental health

More carers are raising concerns over finances and the situation after the crisis passes-especially around unemployment

Any unplanned hospital admission or illnesses could have a dramatic effect on a family or disabled person relying upon family carers support

Cuts to services or support arising when the economy shrinks was highlighted from the earliest responses to the survey but a fortnight later this theme is increasing by a significant number.

### **How carers access information**

Social media is being used widely, especially Facebook which is used by over half of respondents whilst our [website](#) has been used by 31%.

Around one in ten people that have a smartphone do not use it for accessing social media. Encouraging people to maximise the potential of existing smartphones might increase the levels of support hard pressed families receive – not all people realise the potential of their mobile phones!

Our SMS texting service was highlighted by several carers as being very helpful as were dedicated emails being sent to families.

93% of respondents report having regular information from the Parents Federation through one or more of our mechanisms