

The impact of COVID-19 on People Affected by Dementia

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A survey by
Alzheimer's
Society

July
2020



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Executive Summary

(Part 1 of 5)

Key:

PABD – People affected by dementia

PLWD – People living with dementia

Effect of lockdown on symptoms of dementia

- The most common symptoms that PLWD reported having increased since lockdown began were difficulty concentrating (48%), memory loss (47%), and agitation / restlessness (45%)
- PLWD living alone were more likely to report an increase in their symptoms during lockdown compared to PLWD living with others. In particular: Memory loss (54% v 42%) and difficulty in reading or writing (35% v 24%)
- Only 1 in 5 reported having seen no difference their dementia since lockdown began
- The most common symptoms that carers reported, in their loved one with dementia, that have increased since lockdown began were memory loss (54%), difficulty concentrating (47%), and agitation / restlessness (49%) and stress or depression (46%)
- Carers living with their loved one with dementia are significantly more likely to notice any increased or new symptoms compared to those living away

Executive Summary

(Part 2 of 5)

Impact of lockdown on PLWD and carers

- Nearly half (46%) of PLWD state that the pandemic has had a negative impact on their mental health, and over 1 in 3 reported having lost confidence in going out and carrying out daily tasks.
- PLWD living alone reported their experience of the pandemic the most negatively – with 56% stating that they feel lonelier, compared to 23% of PLWD living with others reporting this.
- Several PLWD mentioned that they missed taking part in social functions that attended prior to lockdown (including dementia support groups), and that the restrictions on doing this has diminished their confidence further.
- The pandemic has had a strong negative emotional impact on carers with their mental health (44%), added strain in their relationship with their loved on (42%) and left them struggling with caring for themselves and their loved one (22%).
- Other areas carers have been negatively impacted include exhaustion, sadness and missing loved ones

Executive Summary

(Part 3 of 5)

Communicating and going out during the pandemic

- Nearly 1 in 3 reported having spent more than 7 days at home during lockdown and PLWD living alone have spent the longest time without going outside (more than 6 days: 57%) during lockdown followed by carers living with PLWD (more than 6 days: 43%)
- Half of the respondents reported having had in-depth conversations at least once every other day but this is significantly lower among PLWD living alone (31%) and carers living with PLWD (37%).
- Half of respondents reported fewer in-depth conversations now than before lockdown particularly PLWD alone (60%) and carers living with PLWD (57%).

Executive Summary

(Part 4 of 5)

Since the easing of lockdown rules

- Over half of all respondents reported meeting with family / friends outdoors since the easing of lockdown rules. However, only 19% of PLWD who are living alone reported doing this.
- PLWD living alone were the group who were least confident going outside since the easing of lockdown rules – with 1 in 3 stating they felt this way.
- Other outdoor activities that both carers and PLWD commonly mentioned doing were gardening-related - for example, visiting allotments and gardening centres. This ties in with the renewed interest in gardening that has been reported since lockdown began.
- A number of carers reported taking advantage of the easing of lockdown rules by going for drives with the PLWD that they care for – in addition to recommencing hobbies that they had before lockdown e.g. golf and bowls.

Executive Summary

(Part 5 of 5)

Current and future support and care

- 41% of those who receive a care and support package reported this having been reduced or stopped since lockdown began. However, most respondents (57%) stated that they did not receive these services in the first place
- Getting the right care is most useful (72%) followed by coping with loneliness and isolation (66%) and decoding dementia specific government advice on Covid-19 specifically for PABD (65%)

Methodology and Respondents Breakdown

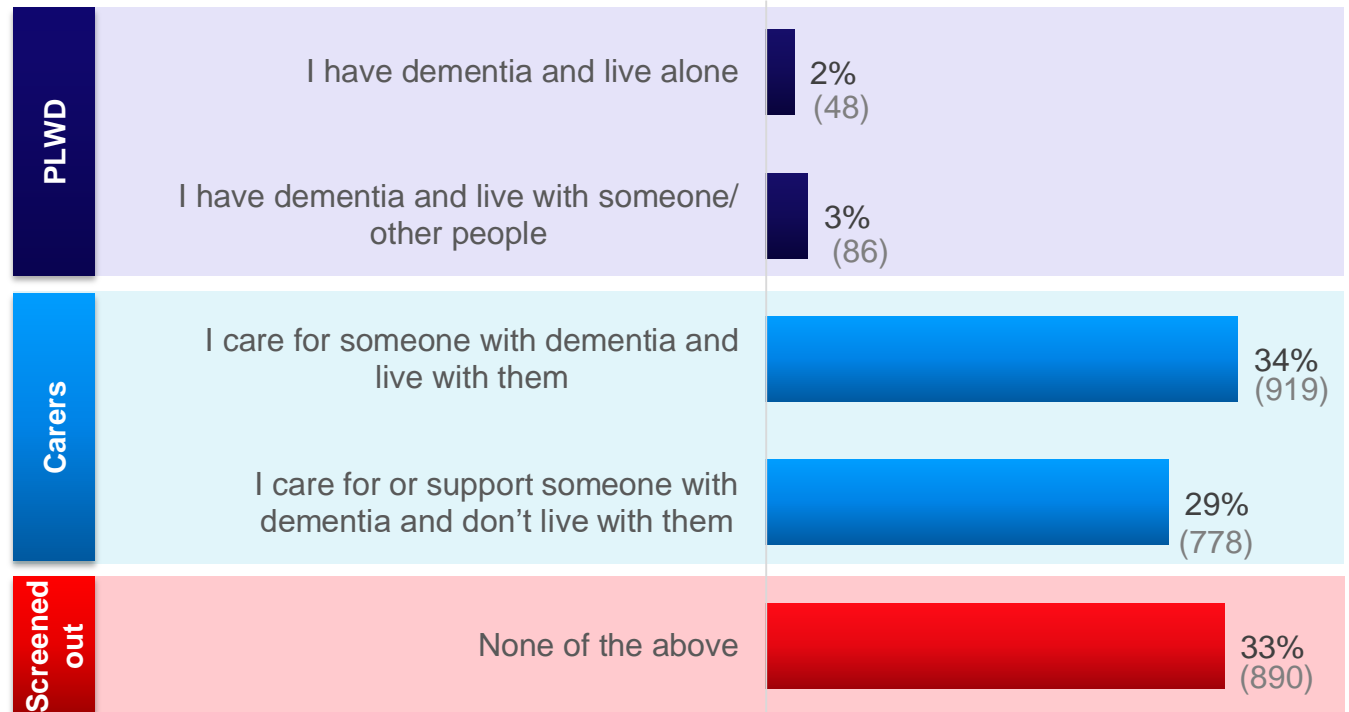
Methodology

A short survey was sent via email to understand the impact that Covid-19 has had on those living with dementia and carers of people living with dementia.

The survey was shared with:

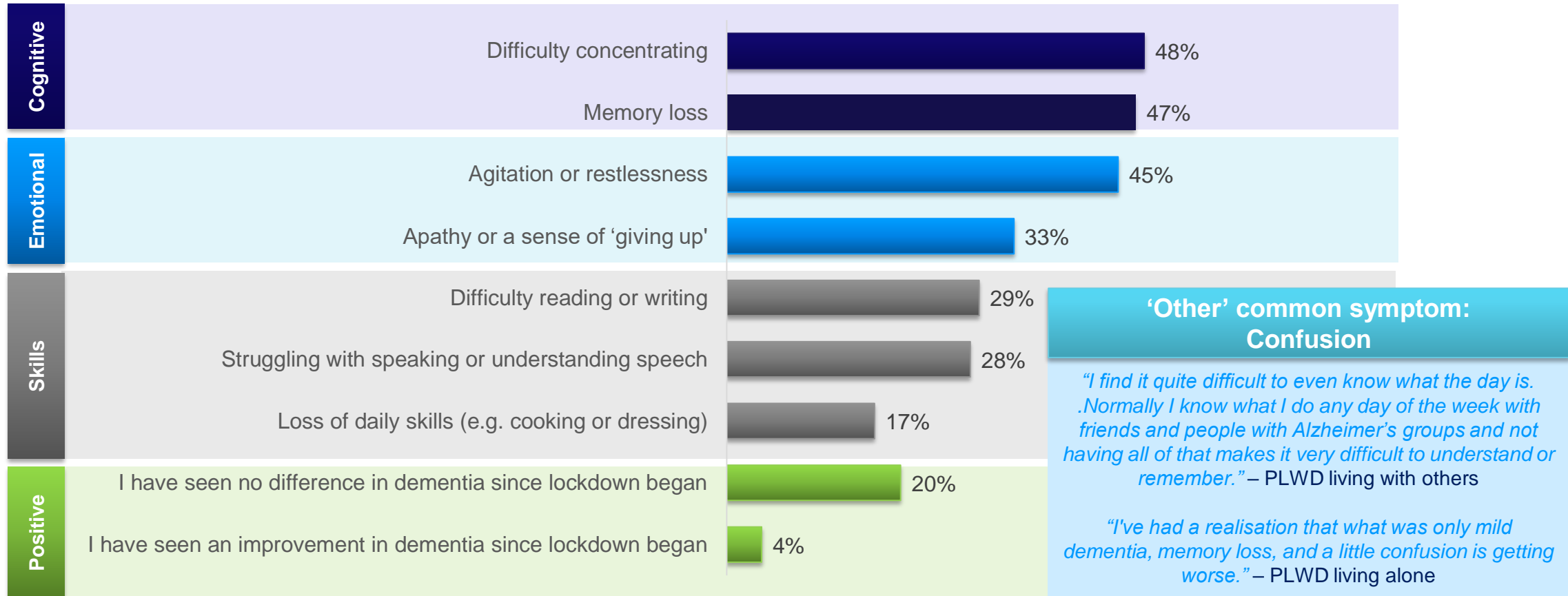
- The National Virtual Network
- The 3NDWG
- The campaigns database
- In the Dementia Friends newsletter
- On twitter
- FODN's facilitators

Respondent's current living situation / connection to dementia



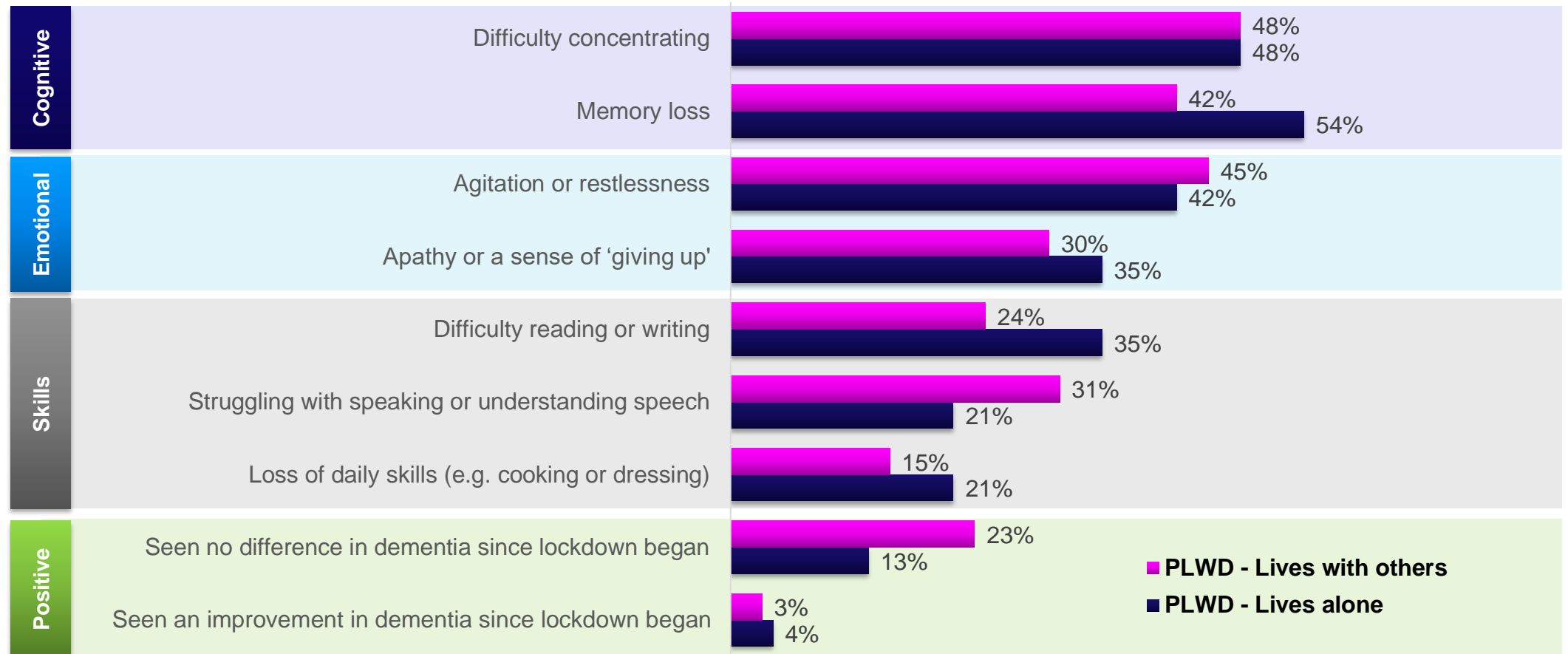
EFFECTS OF LOCKDOWN ON DEMENTIA SYMPTOMS

Since lockdown began, difficulty concentrating and memory loss are the symptoms that PLWD report have increased the most



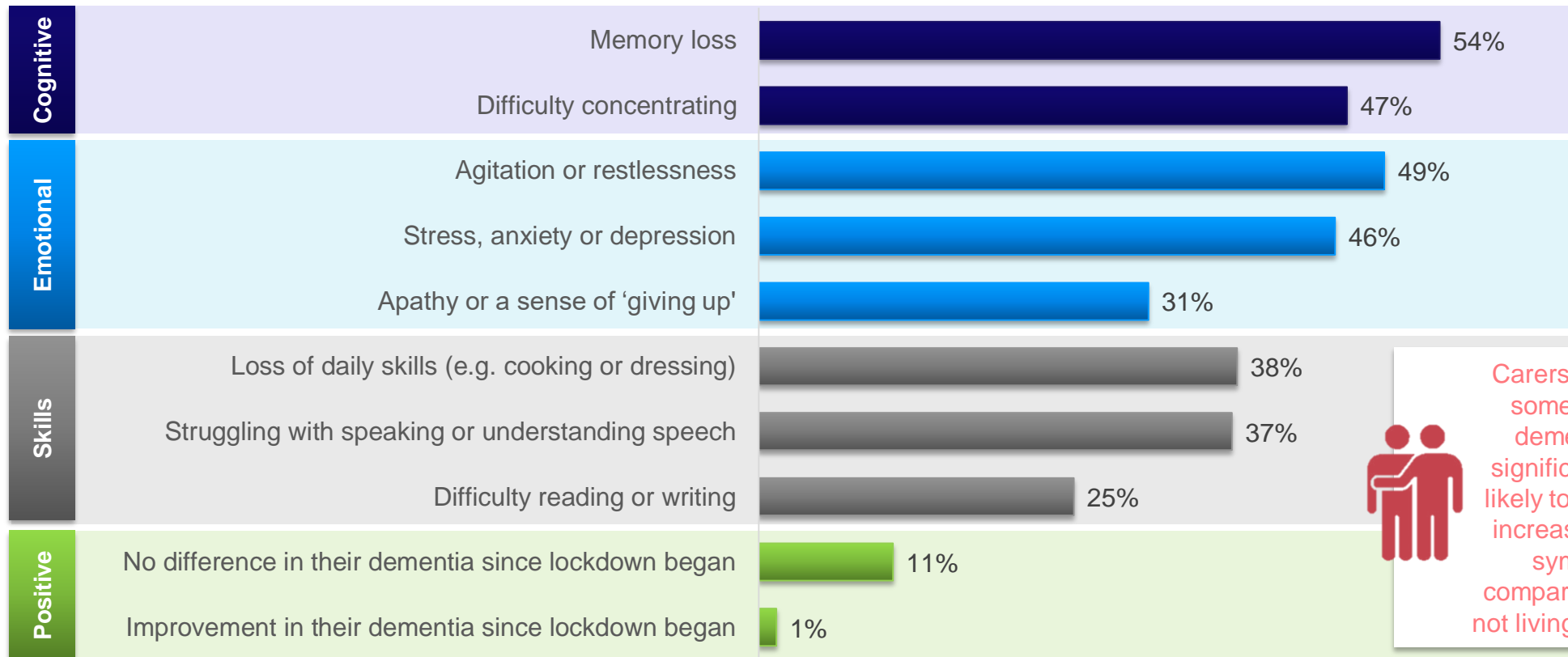
10 Q2. Since lockdown began, have you noticed an increase in any of the following symptoms of dementia in yourself or a loved one? Please tick all that apply. Base=132

PLWD living alone were more likely to report an increase in their symptoms during lockdown than those living with others



11 Q2. Since lockdown began, have you noticed an increase in any of the following symptoms of dementia in yourself or a loved one? Please tick all that apply. Base=132

Since lockdown, carers have noticed cognitive and emotional symptoms increase in their loved one living with dementia



Carers living with someone with dementia are significantly more likely to notice any increased or new symptoms compared to those not living with PLWD

12 Q4. Since lockdown began, have you noticed an increase in any of the following symptoms of dementia in a loved one/ someone you care for with dementia? Please tick all that apply. Base = 1694

Other symptoms commonly mentioned are not understanding lockdown, loss of mobility and general health decline

Psychiatric related

"The donepezil began not to work they put her on something else and she started hallucinating. 3 weeks ago she had to be admitted to our local dementia hospital under a section 2 . I be found it very hard to take"

Doesn't understand current situation

"Does not understand the social distancing and that everywhere is closed re socialising in restaurants pubs and activities we used to attend throughout the week."

Aggressive and Emotional

"My husband has become aggressive and will not accept or appreciate help that is offered He just wants to sit in the chair and sleep."

Loss of mobility

"Loss of muscle mass, strength and stability leading to being more wobbly, more risk of falling, and this is due to not being able to leave the property. A trip to a garden centre has not been possible with shielding."

General decline

"I have seen a deterioration in dementia, energy levels down sleeping a lot we had plenty of seeing people and getting out I as husbands carer have been shielding so he has not seen anyone or got out."

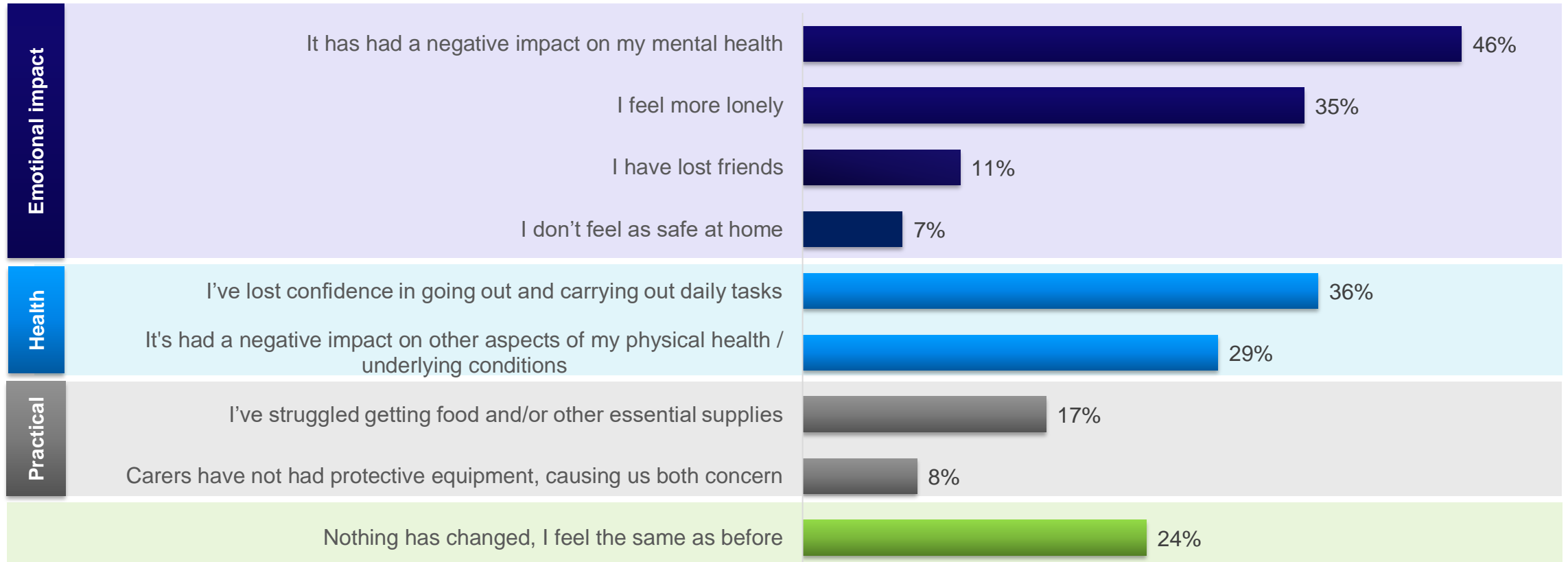
? Some said they have not been able to see their loved one during lockdown and so they are unaware of their condition.

= Those with loved ones in much later stages of the disease state that the lockdown has had no impact because they are not aware of it.

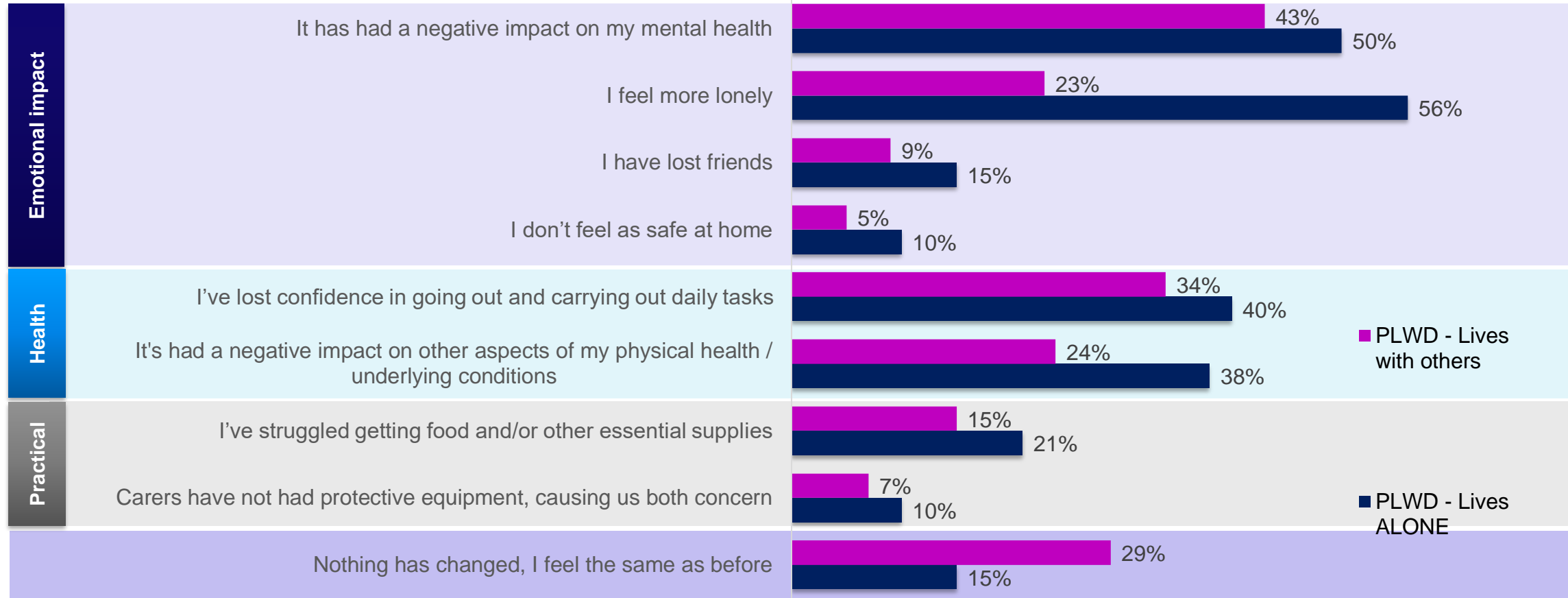
13 Q4. Since lockdown began, have you noticed an increase in any of the following symptoms of dementia in a loved one/ someone you care for with dementia? Please tick all that apply. Base = 385

IMPACT OF LOCKDOWN ON PLWD AND CARERS

Nearly half of PLWD state that the pandemic has had a negative impact on their mental health and a third feel lonely



PLWD living alone reported their experience of the pandemic the most negatively – particularly in relation to loneliness



Other effects commonly mentioned by PLWD are having to rely on others, less socialising and experiencing a sense of loss

More reliance on others

"I have put a lot of responsibility onto my wife. Normally when she is out working I can go to the shops myself - unfortunately my doctor has told I must keep away from shops so my wife has to fit shopping between her work and I feel guilty because I have uploaded extra pressure on her."

– PLWD living with others

Lack of social activities

"I very much miss the Alzheimer's groups that I normally go to. I have a group meeting about all sorts of different things on a Tuesday, and on Wednesday I go to Book Group."

– PLWD living with others

"Not mixing with all the people you had a relationship with: Probus and all those groups. Communication not as good as it used to be."

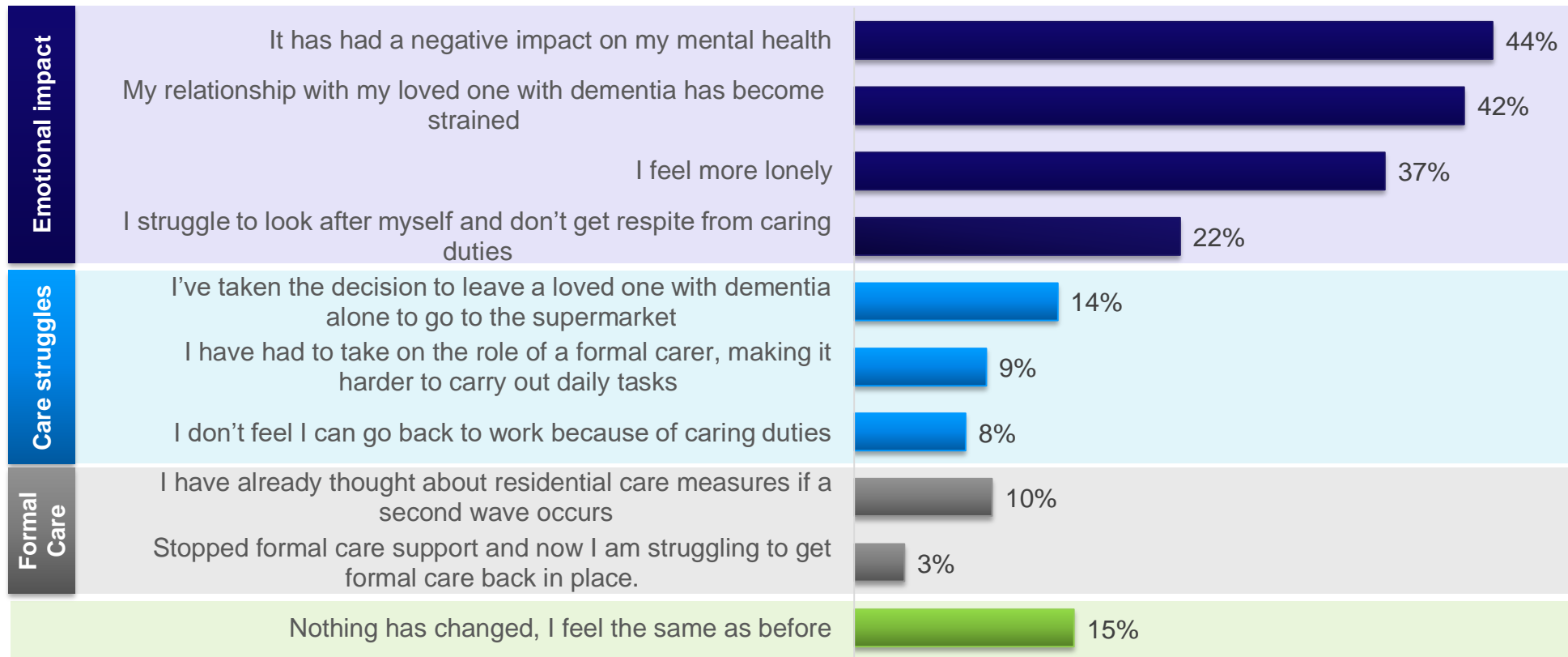
– PLWD living with others

General sense of loss

"I have an Alzheimer's society adviser who keeps in touch with me regularly by email and telephone and friends who text/ phone, so I am aware and grateful for all I have. But I still feel that covid-19 has robbed me of some of my remaining years living with dementia/Alzheimer's rather than the years when I will be reliant on other people totally."

– PLWD living alone

The pandemic has had a strong negative emotional impact on carers and left them struggling with caring for their loved one



Other impacts commonly mentioned by carers include exhaustion, sadness and missing loved ones

Exhaustion

"I work full time and this has continued but my caring duties have increased 3 fold. I am exhausted mum is so unsettled and often violent too now"
"I am managing but frustrated by the whole process because it takes up so much of my time."

Difficult to complete tasks

"Feeling isolated not able to see anyone outside of our four walls only once a week when shopping. Having to rush round not to leave my husband for too long has made me hate shopping now. The fear of taking the virus home to him or me getting it."

Sadness and missing loved ones

"Due to lockdown and mum isolating in a care home in West Sussex, as I live in Cornwall I haven't been able to visit her since January and I miss her and she can't understand why. I miss her so much"

Missing other family members

"As a carer for my wife I am sometimes finding life difficult as I am also shielding as I suffer with CML and miss face to face contact with family and friends."
"I miss the company of others which I enjoyed prior to lockdown when I'm on respite leave."

Frustration

"Frustration and harder to keep my patience with 'demands'."
"I feel frustrated that people with dementia and their families have been left to cope with minimal support."

Guilt

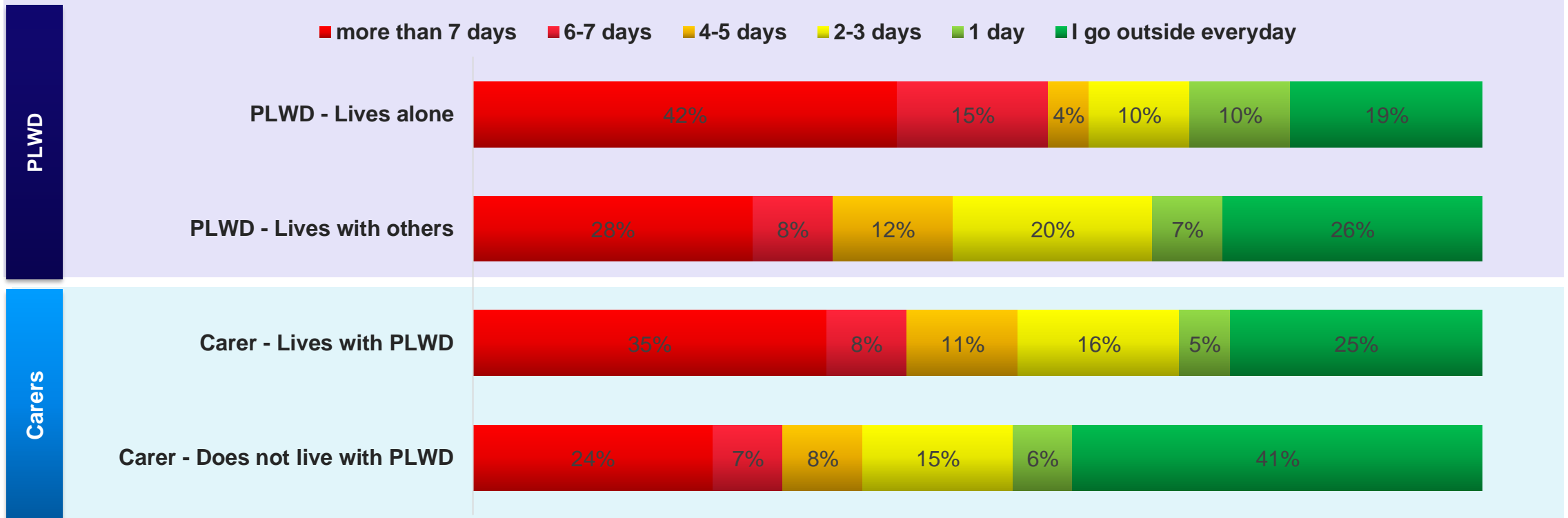
"I feel extreme guilt that I can't visit my mother properly, she can't understand why I won't enter her care home. I feel distraught watching her cry or refuse to come to the window to see me."
"Left with awful memories of not being there for him."

COMMUNICATING AND GOING OUT DURING THE PANDEMIC

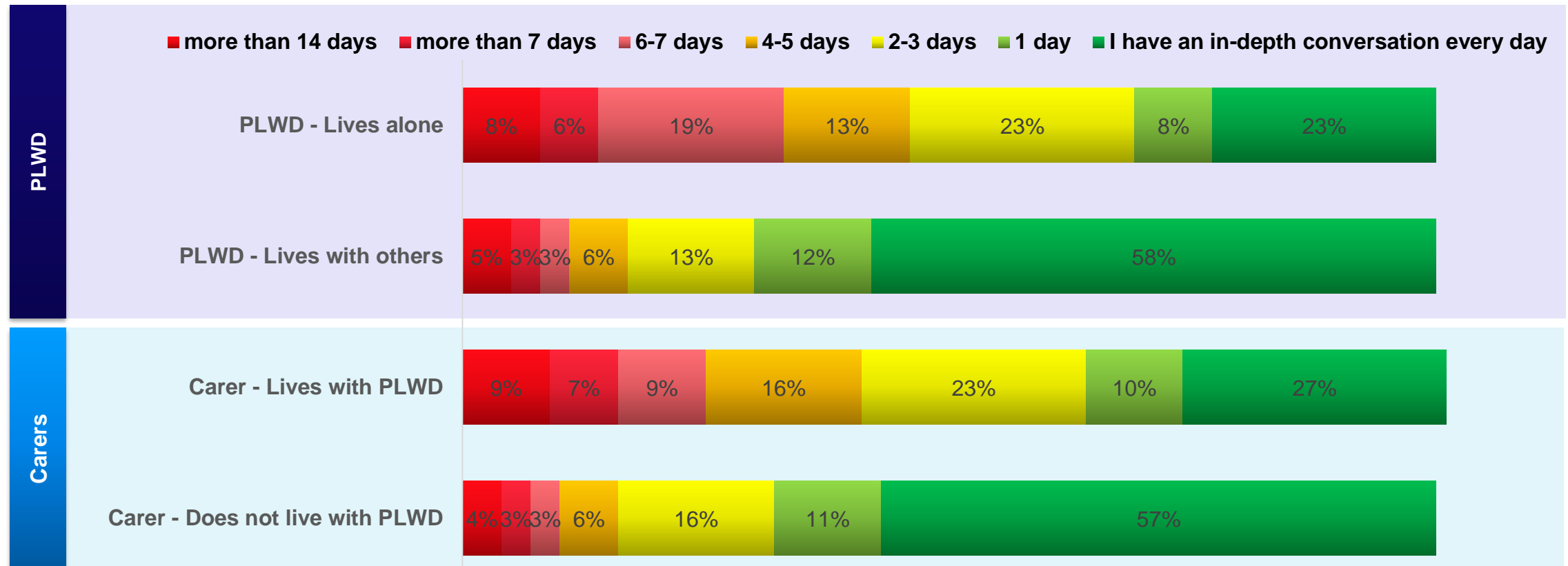
PLWD living alone have spent the longest time without going outside during lockdown followed by carers living with PLWD

What is the longest time respondent has spent without going outside?

■ more than 7 days ■ 6-7 days ■ 4-5 days ■ 2-3 days ■ 1 day ■ I go outside everyday



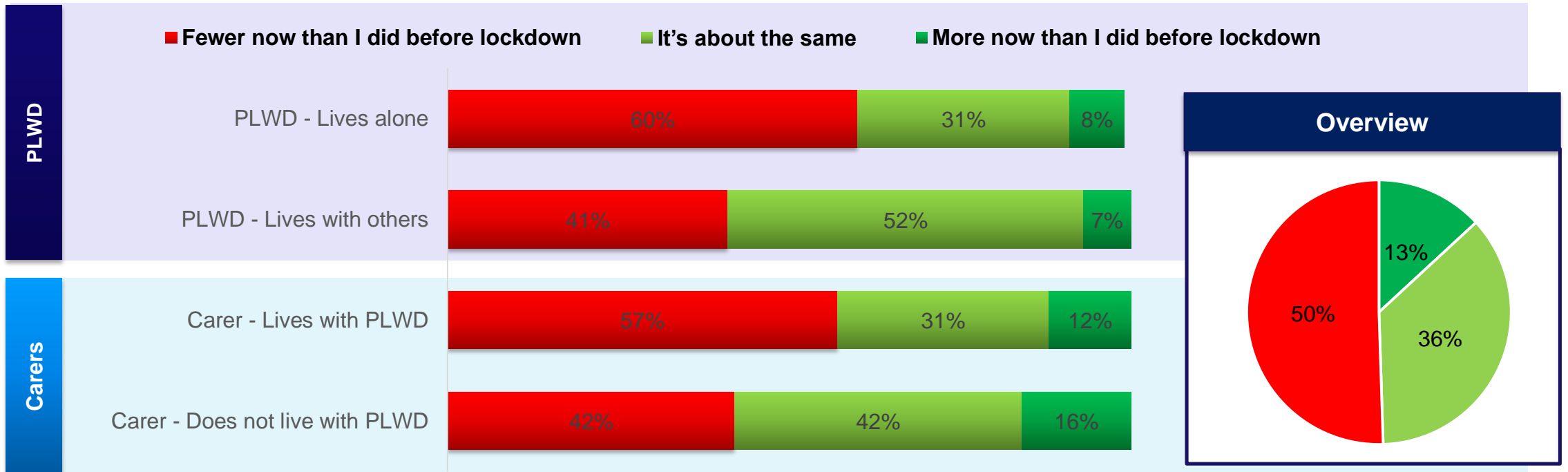
PLWD living alone and carers living with PLWD have spent the longest time without having an in-depth conversation



22 Q8. Since lockdown began, what's the longest you've gone without having an in-depth conversation with someone (in this case in-depth means a conversation more than 5 minutes)? Base=1,831

Half reported fewer in-depth conversations now than before lockdown particularly PLWD alone and carers living with PLWD

Comparison to how many in-depth conversations respondent had before lockdown

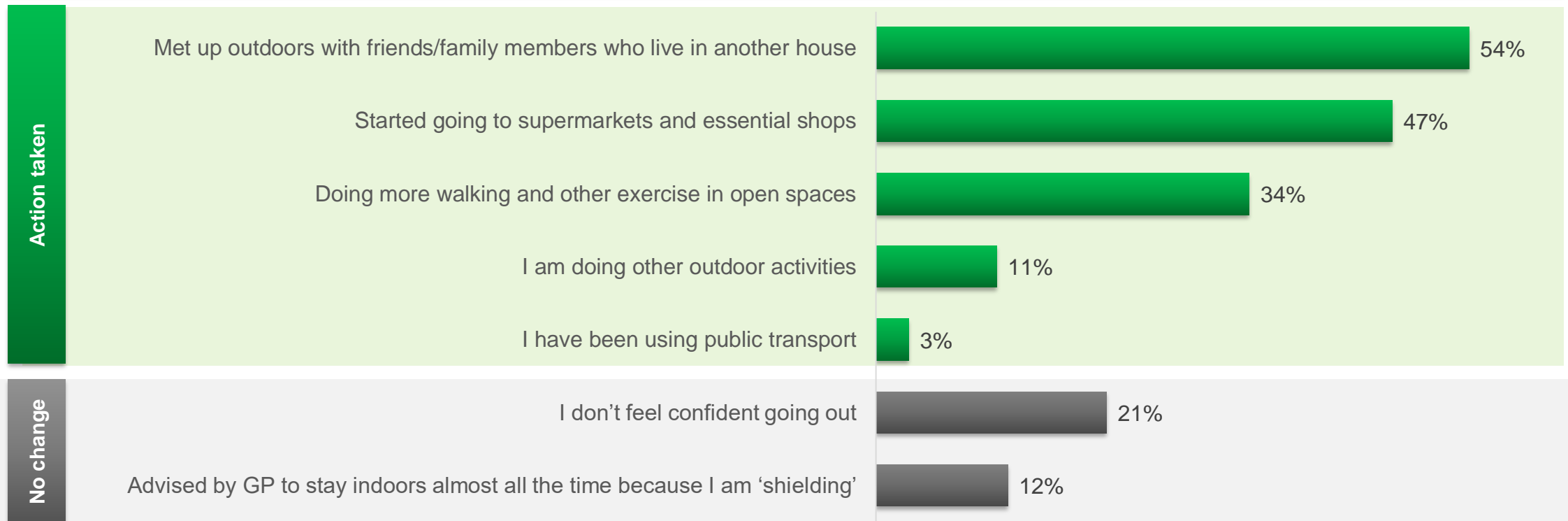


23 Q9. Thinking about your answer to the previous question, (about in-depth conversations), how does your experience now compare to how often you had in-depth conversations (longer than five minutes in this case) before lockdown?
 Base=1,831

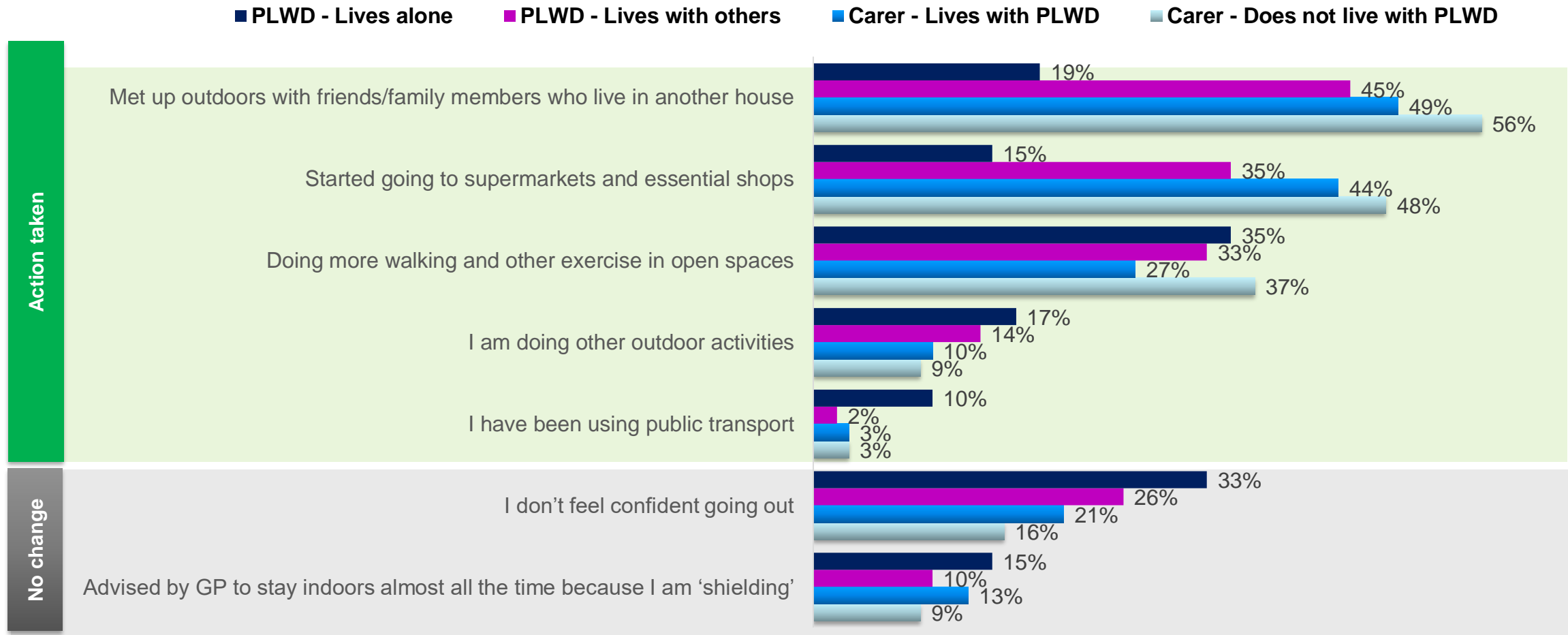
SINCE THE EASING OF LOCKDOWN RULES

Over half of respondents reported meeting with family / friends outdoors since the easing of lockdown rules

What actions has respondent taken since rules around lockdown have changed?

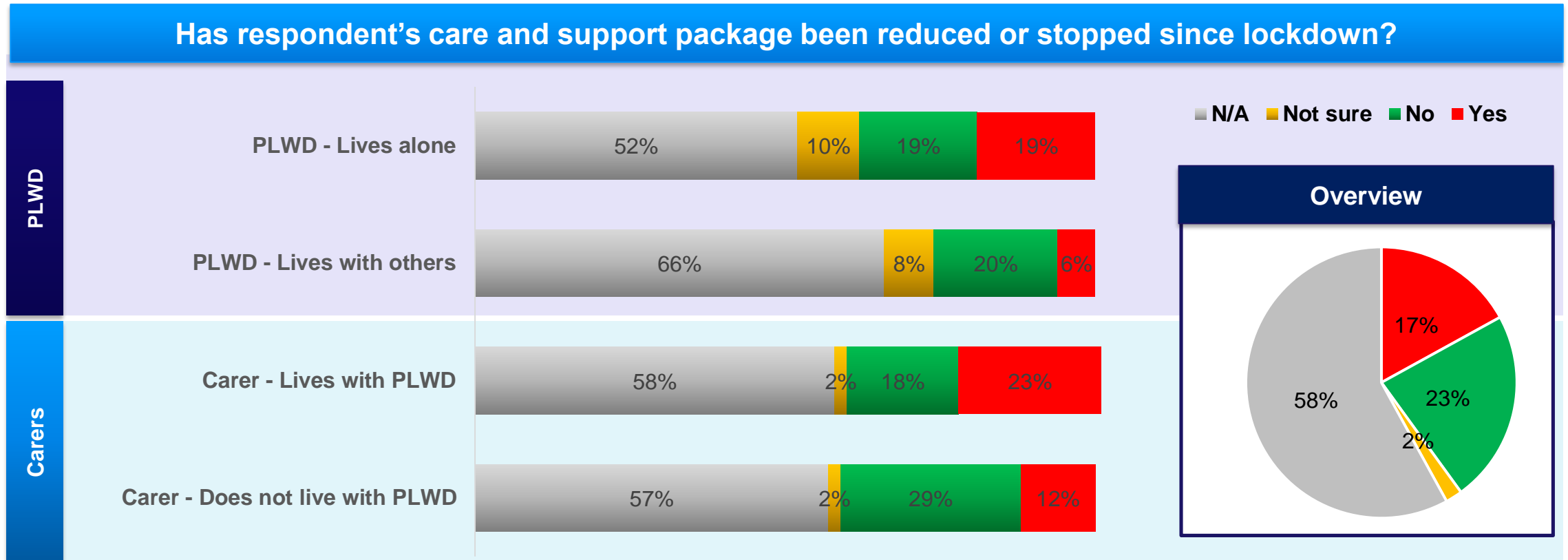


PLWD living alone were least confident going outside since the easing of lockdown rules



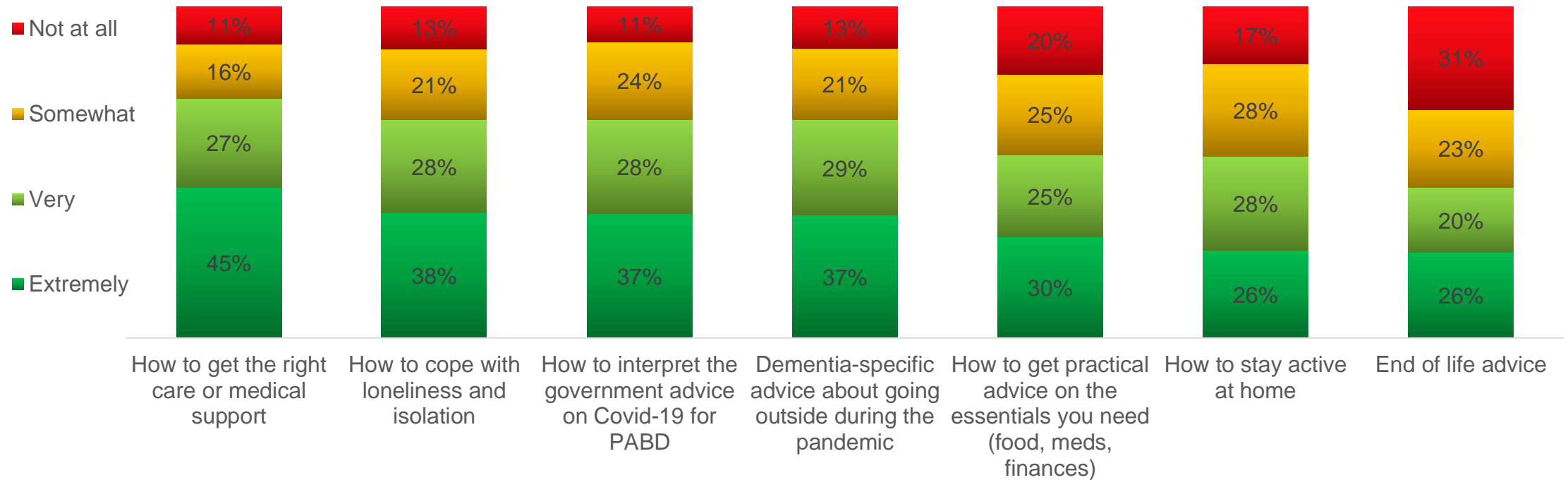
CURRENT AND FUTURE SUPPORT AND CARE

Nearly half of those who receive a care and support package have had this reduced or stopped since lockdown began



Getting the right care is most useful followed by coping with isolation and decoding dementia specific government advice

Support that would be most useful around coronavirus



29 Q11. How useful would it be for Alzheimer's Society to provide the following support around coronavirus (extremely, very, somewhat, not at all). Base = 1831