Briefing for MPs:
A new legal right to a Care Supporter

For backbench business debate: Thursday 27th Oct
2pm-5pm, House of Commons main chamber
"Guaranteeing the Right to Contact in Care Settings"

What’s the problem?
Over the past two and a half years we’ve seen the devastating impact of people being isolated in health
and care settings, denied contact with their family and friends. The damage done to peoples’ health and
wellbeing has been tremendous. It cannot be allowed to happen again.

In fact, people are still facing the end of their lives in
hospitals and care homes separated from loved
ones. Many families still experience major and
traumatic difficulties when trying to support their
relatives in health and care settings.

During the pandemic we have seen that advisory
guidance on visiting has proven ineffective at
protecting the rights of those in health and care
settings.

Although there are some excellent examples of
good practice, there is too much uncertainty and
variability throughout the system. The regulator, the
Care Quality Commission (CQC), has proved
ineffective at monitoring compliance with non-
statutory guidance on visiting.

It is also important to stress that this situation was
exacerbated by, but is not exclusive to, the
coronavirus pandemic. In the years preceding the
pandemic we supported helpline clients who were
banned from visiting care homes after raising
concerns.

New data from the Relatives & Residents
Association and Rights For Residents, who surveyed
over 650 families, highlights how the harm of isolation
continues to this day:

- Visiting restrictions during the majority of coronavirus outbreaks between April-Sept were
  more restrictive than advised by current Government guidance:
  - 1 in 5 outbreaks saw residents confined to their rooms
  - 1 in 9 outbreaks saw residents not allowed any visitors at all
- Care homes are still implementing blanket visiting restrictions outside of outbreak situations,
  contrary to current guidance:
  - 45% of respondents said there were visiting restrictions in place despite there being no
    outbreak

“I was grateful that I could be with [my wife] in her last moments but I was so upset
that I couldn’t have had some other
moments with her while she was conscious.”
Husband of hospital patient, Sept 2022

“They seem to make their own rules at this particular home. I do not feel comfortable
reporting to CQC as I’m worried about
backlash inside the home.”
Relative of care home resident, Sept 2022

“After raising concerns about the lack of
care of my mother in law, I was accused of
being abusive and banned. The Local
Government Ombudsman overturned the
ban, as the manager could not provide any
evidence of their accusations. But it took
over a year to resolve.”
Relative of care home resident, 2017
What’s the solution?
The charity the Relatives & Residents Association and campaign groups Rights For Residents and John’s Campaign are calling for a new legal right to be introduced to guarantee people’s access to in-person support from at least one ‘Care Supporter’ – a person important to them such as a relative or friend. This right could be quickly introduced as a statutory instrument in health and care regulations.

Care Supporters would be able to visit or accompany a person in any health and care setting. Health and care services already accommodate for other types of support such as interpreters or even assistance dogs, and a Care Supporter would make health and care professionals’ work easier. The Care Supporter would be someone who knew the person, and would be able to help them communicate their wishes and needs to ensure they got the right care.

The duty would lie on care/health staff to facilitate this contact, and would be monitored and enforced by the regulator. Putting this into law would ensure the CQC take action and do not continue to leave people needing care and their families bereft. Restrictions on this right would only be permitted where it is necessary to protect from a known and immediate risk of harm from the Care Supporter (they are infectious or for safeguarding) and must be proportionate to that risk. This would build on and add to existing legal duties, such as in the Human Rights Act.

What you can do to help
1. Attend the debate on Thursday 27th October, 2pm-5pm
2. Speak in support of this new law – below are some key points you might like to make:
   - Never again should the vital support of relatives or friends be denied
   - Lessons must be learned from the pandemic when we saw the devastating harm to both mental and physical health of isolation in health and care settings
   - We must recognise in law the crucial role family carers play in the lives of people in vulnerable situations
   - Access to a ‘Care Supporter’ should become a routine, key ingredient for good care, which one day any of us could need
   - The support of partners, parents, sons and daughters is not an optional extra, but vital to dignified care

Contact R&RA for more information: 07385 290 059 or info@relres.org

Support for this new law
35 organisations signed up to support the call for a new legal right to a Care Supporter, including Healthwatch, Mind, Mencap, Alzheimer’s Society, Parkinson’s UK, Dementia UK and Disability Rights UK, as well as many care providers. Full details: https://www.relres.org/care-supporter/
The call for a new law has already received cross-party support:

- An event in Parliament on 8 March saw overwhelming support from across the political spectrum: https://www.relres.org/parliament-care-supporter/
- Over 60 MPs signed a joint letter to the Secretary of State for Health and Social Care calling for this new law in May: https://www.relres.org/mp-letter-care-supporter/
- A cross-party coalition of MPs is taking this call forward: Labour MP Dan Carden, Conservative MP Tracey Crouch, Liberal Democrat deputy leader Daisy Cooper, and Plaid Cymru Westminster Leader Liz Saville Roberts

Helen Wildbore, Director of the Relatives & Residents Association, said:

“People who need care must never again be isolated from those most important in their lives. Relatives and friends are much more than just ‘visitors’, they are a lifeline and shouldn’t face a battle to be recognised as a vital part of the care team. A new right to a ‘Care Supporter’ is urgently needed to end the terrible harm caused by isolation now and for years to come.”

About R&RA

The Relatives & Residents Association (R&RA) champions the rights of older people needing care in England. We provide information, advice and support to empower older people and their families/friends, and use their unique perspective to raise awareness and to influence policy and practice. The R&RA Helpline has been supporting people at the sharp end of the pandemic, giving us a unique insight into the experiences of families dealing with coronavirus and measures taken to manage it.