The Care Partner

Additional information to further support implementation of the care partner concept

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Introduction

During the ongoing Covid-19 pandemic, a series of restrictions have been applied to previously established hospital, hospice and care home visiting arrangements to prevent, or mitigate the impact of unintended spread of infection.

There is no easy answer to the challenge faced in reducing the serious harm caused by Covid-19 transmission in care homes and there are challenges which care homes, as distinct from other health and care settings, face in protecting all residents from infection.

Evidence from the first surge of Covid-19 here, and across the world, has shown that reducing footfall by the restriction of visitors to care homes has been a key strategic component of managing the pandemic. It was introduced to protect residents, their families and staff by reducing the risk of infection into care homes and is a key protector for some of our most vulnerable in society. Information gathered through the Rapid Learning Initiative into the Transmission of Covid-19 into and within Care Homes in Northern Ireland[1] indicated that care home managers believe that reducing footfall through the care home, including that of visitors, was one of the most effective measures in minimising transmission of infection.

The currently available evidence[2] related to care homes indicates that it is difficult to analyse specific cause of infection transmission as environments change quickly. Current evidence represents the best available evidence at this time, and details are subject to update as new evidence emerges. Whilst studies do not rule out any route for entry of infection to a care home (staff, visitors, visiting professionals, new or returning resident admissions and so on), the evidence notes that is important not to generalise or to place emphasis on one route of infection over other routes without clear evidence; studies undertaken so far indicate multiple introduction routes are possible. Further research in various areas, such as the influence of physical layout of the home, ways of staff working and cohorting of residents, is required to further develop preventative and management strategies. However, modelling studies have demonstrated that allowing visiting to a care home has only a marginal impact on increased risk of infection.

[1] Rapid Learning Initiative into the Transmission of Covid-19 into and within Care Homes in Northern Ireland https://www.health-ni.gov.uk/publications/rli-final-report

[2] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/925141/S0780_Social_Care_Working_Group_update_paper.pdf

Whilst research continues and we learn more about this infection it is prudent continue to take precautions to minimise risk of unintended spread of infection. This will involve robust internal infection prevention and control measures and advised public health protective measures (Personal Protective Equipment (PPE); limiting person to person close contact; good hand hygiene; good respiratory hygiene; frequent environmental cleaning). Implementing these measures will affect the day to day management of the care home and unfortunately will have an impact on visiting arrangements, with advised limitations for visiting based on the particular Alert level at any one time.

Additional funds have been made available to care homes for enhanced cleaning requirements. Funding has also been made available to support the extra tasks associated with management of visiting and care partner arrangements, possibly to support a "visiting champion" in each care home.

The need for restricted visiting arrangements has no doubt contributed to an emotional trauma caused by the separation of residents from those they are closest to. The very real distress to residents that can result from restricting visiting is recognised. Also recognised is the fact that visiting and those significant connections with families, carers and others are themselves important strategies for reducing the risk of preventable harm since those who know the resident best can be uniquely attuned to changes in their behaviour or status.

An open letter, signed by a number of infection prevention and control experts and concerned individuals, supported by the Infection Prevention Society[3], advises that infection prevention and control measures, such as restricted visiting arrangements "are often disproportionate to the realities of nursing, care and residential homes, and at odds with what is required for compassionate, kind and safe care." It must also be acknowledged that imposing a ban on visiting has serious implications in terms of potential breaches of Article 8 Human Rights, the Right to Private and Family Life[4]. Whilst the Department of Health (DoH) in Northern Ireland's guidance for care homes (Version 1, issued 17 March 2020) was clear that advice to restrict visiting did not amount to a "blanket ban", nonetheless, it is recognised that in many cases that the restrictions implemented in care homes effectively "banned" face to face visiting for a period of time.

In recognition of the distress for residents and their families as a result of restricted visiting arrangements, the widely recognised need to balance risk of infection with physical and psychological needs and emerging evidence around routes of infection

[3] Open letter: Infection prevention and control should never be at the expense of compassionate care https://www.nursingtimes.net/opinion/open-letter-infection-prevention-and-control-should-never-be-at-the-expense-of-compassionate-care-16-10-2020/

[4] European Convention on Human Rights https://www.echr.coe.int/Documents/Convention_ENG.pdf

in care homes, revised guidance[5] was published on 23 September 2020 and included the following:

"*Each care home should work to introduce and support "care partner" roles."*

"Care partners will have previously played a role in supporting and attending to their relative's physical and mental health, to ensure that other health and social care needs are met due to a pre-existing condition".

The underlying concept for the role of a care partner is to find a balance between mitigating the impact on the health and wellbeing of residents through the transmission of Covid-19 by restricting access to care homes, and mitigating the impact on the health, wellbeing and the human rights of residents by restricting access to those who had been providing an essential element of support to the resident's physical and psychological well-being.

Families and friends need to see their loved one to be reassured about their well-being. Equally families and friends need to understand the strains and pressures on those who are caring for their loved one, as a consequence of the continuing pandemic situation. Achieving the balance in protecting residents from infection and protecting the other factors that affect well-being and welfare is difficult to achieve.
We do not underestimate both the practical and the emotional challenges for residents, families and care home staff in seeking to achieve that balance.

Many care homes have successfully introduced a range of innovative ways to try to accommodate visiting safely. Consistent with the other countries of the UK and Republic of Ireland, the focus is now on learning to "live with" Covid-19, meaning that there is a need to continue to safely manage visiting in practical ways which provide meaningful connections for both the resident and their visitor.

To help shape the description of the care partner, a range of people and organisations including representatives of families, care home staff and Independent Sector Providers, Trust staff, including those providing support to care homes, and DOH officials with relevant policy responsibility were asked for views about what they thought being a care partner would entail. These contributions were analysed with some common themes evident throughout the feedback. This has been used as the basis for describing the "Care Partner Concept", which will be subject to ongoing review in the light of experience of the operation of the care partner role.

[5] COVID-19: Regional Principles for Visiting in Care Settings in Northern Ireland https://www.health-ni.gov.uk/Covid-19-visiting-guidance

The Care Partner

The “care partner” is a concept that will be applied differently for individual residents who live in the many different environments that make up the care home sector. Each care home will be responsible for agreeing how the concept will be applied in all of those individual circumstances, with support available from Health and Social Care Trusts.

There is no application process to become a care partner. The care partner role is about relationships. A nurturing, sustained, pre-existing relationship the resident has had with an individual, whether specific to the time living in the care home or established prior to admission, where that connection with the resident is an essential element in maintaining the resident’s mental, physical and emotional health and wellbeing. The care partner is the person, whom without the presence of this individual in their life, a resident is, or is likely to, experience distress.

The care partner may not necessarily be a relative. In many circumstances a close friend may have previously been the person whose contact was critical to the physical and mental health of the resident. At the core of the concept of the care partner role is the quality of that individuals pre-existing connection with the resident and the impact of their absence on the resident’s life.

Care partner contact is in addition to visits to a resident which are organised according to the care home’s visiting policy and the DoH Covid-19 regional principles for visiting.

Where they are able to, the individual resident should self-identify who they want their care partner to be, receiving the appropriate support to do so if required. The resident can discuss and progress this with the care home staff. Alternatively the resident can ask their identified care partner to discuss and progress this with care home staff.

There will be instances where a resident is unable to indicate for themselves if they would wish to have an identified individual act as a care partner. In these circumstances, any decision around introducing a care partner role, defining what the role might be and identifying who might fulfil the role, should be a decision made in the best interests of the resident, considering all of the relevant factors and balancing these considerations. These discussions should involve all relevant persons, which might include relatives/friends/advocates and a number of HSCT professionals alongside the care home staff. In most of these circumstances, the resident’s relative or friend will discuss and progress this with the care home staff. Alternatively the care home manager may identify the resident’s need for a care partner and progress this along with the relative or friend, independent advocate as required, and relevant others.

There may be times that a resident's selection of care partner cannot be facilitated by the care home, for example where adult safeguarding issues have been raised about that individual. This situation will again require a discussion involving the resident, the care home staff, relative/friend/advocate and HSCT professionals to come to an agreed decision on how to proceed.

The care home is not responsible for mediating or settling disputes between individuals who want to be a resident's care partner. However, the care home should have procedures in place for escalating these situations to the resident's HSCT Care Manager or Social Worker. These instances might include where a resident or family member/ friend is dissatisfied with a decision which does not identify a need for the role of care partner, or regarding who is appointed as the care partner and/or when the care home is concerned about the impact such a dispute is having on the health or wellbeing of a resident. In such instances, the resident must be provided with the appropriate support to ensure their voice is heard. This may be the resident's Care Manager or Social Worker or may involve the use of an independent advocate.

A care partner should commit to fulfilling the role whilst advised visiting restrictions due to Covid-19 last, although it is recognised that individual circumstances can change. A care partner must also agree to comprehensively and consistently follow the care home's protocols in relation to infection prevention and control measures, which include but are not limited to cleaning regimes, use of PPE, effective handwashing and limited movement within the home, visiting policies and visiting plans, and health and safety procedures etc. Care partner arrangements may be removed if a care partner does not follow the care home's protocols.

In January 2021, as an additional assurance measure, agreement was reached to include care partners in the Covid-19 care home staffing testing programme. It must be noted that testing alone does not provide protection against infection transmission. Adherence to all the care home's infection prevention and control protocols is still required. Public Health Consultants advise that when the care partner testing regime is implemented, an infection free care partner, adhering to all required IPC measures presents a low risk of infection transmission. So, whilst care partners must consider the implications and risks of acquiring the infection, care partner arrangements for a care partner with a negative test result can continue should a care home be experiencing an outbreak.

An individual should not undertake the care partner role if they, or anyone living with them are self-isolating, are immunocompromised or have had reason to shield for Covid-19 or for any other infection risk identified by their GP.

A care partner must also understand that their presence in the care home increases their relative/friend's person to person contacts and as such must be considered an increased risk to the resident in this unprecedented pandemic period.

Should there be any concerns that the resident is experiencing distress as a consequence of the care partner's presence, adjustments to the arrangements should be agreed with the resident and/or care partner, with support from an independent advocate and the resident's care manager/social worker where necessary.

The Role

The role of care partner is a voluntary role which is complimentary to care home staff. It does not replace, nor is there any expectation that it should replace the existing roles and responsibilities of care home staff or professionals involved which they must continue to fulfil for that resident. The care home manager should make the boundaries between staff and care partner roles very clear and agree with the care partner.

The care partner is not an employee or a formal role, therefore legal and regulatory requirements, such as AccessNI or employment indemnity do not apply.

In many situations, the attention of the care home staff means that residents exhibiting distress – whether manifesting physically, mentally or emotionally – are appropriately cared for by those staff with skill and compassion. In balancing all of the circumstances involved, there needs to be a clearly articulated benefit to the resident to the introduction of a care partner that outweighs the known benefits of reducing visitor footfall through care home premises and an increased risk to both the individual resident, other residents and the care partner for prolonged potential exposure. Clear and regular communication regarding the steps the care home is taking in terms of infection prevention and control and operating within "Covid Secure"[6] measures will be key in reassuring residents, families and friends and the staff team who may be concerned about increased physical presence within the care home by care partners. In addition care homes should have an enhanced and frequent cleaning schedule and care partners will agree to a comprehensive range of infection prevention and control measures which aim to minimise risk of spread of infection.

The resident who would benefit from the introduction of a care partner is the resident who is experiencing the impact of the absence of a specific relative or friend. These signs will in many cases, manifest as a physical deterioration, or increased emotional distress.

But, it must also be noted that the absence of outwardly visible physical or emotional signs does not mean that a resident is not experiencing distress. A care partner could be someone who plays an important role in picking up what a resident is trying

[6] Covid Secure means maintaining: a social distance of 2m where possible; optimal hand and personal hygiene practices; good ventilation; use of PPE where required; use of face coverings

to communicate or is likely to be experiencing. This might be because they know the resident so well and know what is normal for them; they will quickly and easily pick up on discomfort, pain, illness, upset etc.

> *It is the son with intellectual disability whose personal hygiene has deteriorated because he will only shower when assisted by his father.*
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> *It is the mother who had previously been assisted at lunchtime every day to eat her specially prescribed and prepared meal by her daughter, and who now won't eat.*
>
> *It is the father with dementia who cannot understand virtual communications, and who cries because he thinks his daughter must be dead, because she would never abandon him like this.*
>
> *It is the lady who doesn't speak English, so needs a daily visit from her friend who can translate for staff and provide critical information about how she is so staff can respond or seek appropriate and timely assistance.*
>
> *It is the grandmother whose granddaughter walked with her in the garden twice a week but who now is refusing to walk anywhere.*
>
> *It is the husband, who has become lethargic, confused, more physically dependant, not drinking enough and uncommunicative.*
>
> *It is those who had regular and frequent visits, but are now outwardly or inwardly experiencing the emotional trauma of separation and who consider that to be a price too high to pay.*
>
> *It is the mother who is life limited and if visits are limited too will only spend a few hours in total with her family in her last months, instead of as much as possible of the time she has left - the emotional trauma of separation from a relative or friend is more debilitating than any protection from potential infection.*
>
> *It is the resident newly moved to a care home, where the care partner might provide "settling in" care and support and/ or continuity of support for the physical, mental, and emotional health and wellbeing of a resident which is essential to preventing or mitigating significant distress for that resident at that time.*

A care partner is the individual whose pre-existing relationship with that resident and the things they did with or for that resident, prior to restricted visiting arrangements,

are essential to maintaining the resident's health and wellbeing and whose absence from their life brings, or would be likely to bring, distress.

There may be residents whose condition has changed over the last few months and who are distressed or experiencing a decline in their physical or mental health who would now benefit from a care partner arrangement.

In most circumstances, where it is agreed that a care partner arrangement will benefit the resident, the care partner will simply resume doing the important tasks that they did before the visiting was restricted, although that may not be at the same frequency or duration as before. In some situations this will be based on written needs/ risk assessment for the individual resident which will reflect what the risks are to the resident's health and wellbeing and agreed with the resident and with the care partner.

The tasks undertaken by the care partner may require a level of proximity contrary to public health physical distancing advice. In these circumstances the risks to both the resident and care partner must be discussed in detail when agreeing the care partner contact arrangements, with clear acknowledgement and acceptance by all involved of the potential consequences of close contact.

Agreed care partner arrangements should be included in individualised visiting plans which will include the expectations for the care partner in terms of frequency and duration of care partner contact, adherence to care home protocols and communication with care home staff. The arrangements should be evaluated as part of review of the resident's individual visiting plan.

There is no defined frequency or duration for care partner contact. This will depend on the individual circumstances for each resident and their individual risk assessment.

For example, it might be agreed that on one day a week a care partner will be with the resident for an hour to assist with personal hygiene as they did previously, and on one other day of the week a care partner attends for 30 minutes to provide emotional support.

Or, it might be that 15 minutes every other day is what is needed to reduce the emotional distress of a resident with dementia.

The agreed frequency and duration of any agreed contact should be kept at a level which (in accordance with risk assessment outcomes) manages the balance of minimising the risks of infection for the care home as a whole as well as individual residents, with the benefits of a care partner arrangement.

Every circumstance where it is agreed that a care partner arrangement would be beneficial to a resident will be different and centred around that individual resident's

needs; care partners should not compare their arrangement with any other agreed care partner arrangement.

Where necessary, a care partner role may be shared by up to two nominated persons with only one care partner present at the agreed times.

Monitoring of implementation

The Regulation and Quality Improvement Authority

The Regulation and Quality Improvement Authority (RQIA) will review implementation of visiting guidance and the care partner arrangements as part of their planned programme of inspection, including the use of dynamic risk assessment and individualised visiting plans.

Health and Social Care Trusts

Health and Social Care Trusts will provide support to care homes in implementing visiting guidance and the care partner concept. HSCTs will provide assurances that care homes which accommodate their clients are operating in accordance with visiting guidance that includes the requirement for dynamic risk assessment, visiting arrangements and the care partner approach. This may include:

- providing support and advice where there are difficult to navigate situations relevant to a particular HSCT client;
- considering if the arrangements in place for individual clients recognises the balance in managing infection transmission with protecting the mental health and emotional well-being of residents and takes account of each client's personal health and care needs (e.g. those who may be hearing impaired, visually impaired, cognitively impaired etc.);
- considering if the arrangements in place recognise and facilitate the role of care partners;
- ensuring that individual clients and their relatives have been involved in agreeing visiting arrangements, recognising that residents and/or their representatives should be involved in the individual discussions and decision-making about their own tolerance of risk and their own judgements about the balance of risks; and,
- ensuring that there are mechanisms for ongoing review of clients' individual visiting arrangements.

Health and Social Care Board

The Health and Social Care Board will implement a process to seek continuing assurances from HSCTs regarding care home implementation of visiting guidance which includes dynamic risk assessment, visiting and care partner arrangements.

Annex A

Sources of information

- Alzheimer's Society Briefing (2020) Visiting arrangements in care homes – Summary July 2020 https://www.alzheimers.org.uk/sites/default/files/2020-07/Local%20Authority%20briefing%20%20Care%20Home%20visit%20guidance.pdf (accessed 15/10/2020)
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- TIDE (2020) The experiences of carers of people with dementia during the COVID19 pandemic https://www.tide.uk.net/resources/impact-of-covid-19-lockdown/ (accessed 15/10/2020)

Annex B

With thanks to the following contributing organisations and individuals:

Aughnacloy House
CHASNI
Department of Health Professional Officers
Domestic Care NI
Donna Duffy
Faith House
Families Involved NI
Four Seasons Healthcare
Healthcare Ireland Group
Independent Health and Care Providers
Northern Health and Social Care Trust
Patient and Client Council supported family/carer engagement group
Public Health Agency
Relatives Dementia Care / Support Group
Rose Lodge Private Nursing Home
Rosemary Wilson
Royal College of Nursing Northern Ireland
Ryland Nursing Home
South Eastern Health and Social Care Trust
Southern Health and Social Care Trust
Spa Nursing
TIDE UK
Western Health and Social Care Trust