

Producing 'Top Tips' for care home staff during the COVID-19 pandemic in England: rapid reviews inform evidence-based practice but reveal major gaps

Abstract

Context

The work presented in this paper was undertaken during the first three months of the COVID-19 crisis in the UK.

Objectives

The project aimed to respond to questions and concerns raised by front-line care staff during this time, by producing research-based 'Top Tips' to complement emerging COVID-19 policy and practice guidelines.

Methods

Eight rapid, expert reviews of published, multidisciplinary research evidence were conducted to help answer care home workers' questions about 'how' to support residents, family members and each other at a time of unprecedented pressure and grief and adhere to guidance on self-distancing and isolation. A review of the emerging policy guidelines published up to the end of April 2020 was also undertaken.

Findings

The rapid reviews revealed gaps in research evidence, with research having a lot to say about what care homes should do and far less about how they should do it. The policy review highlighted the expectations and demands placed on managers and direct care workers as the pandemic spread across the UK.

Implications

This paper highlights the value of working with the sector to co-design and co-produce research and pathways to knowledge with those who live, work and care in care homes. To have a real impact on care practice, research in care homes needs to go beyond telling homes 'what' to do by working with them to find out 'how'.

Key words: care homes, COVID-19, policy review, expert review, social care, skilled care.

Acknowledgements and Declarations

This work was supported by the National Institute for Health Research (supported by the NIHR Applied Research Collaboration (ARC) East of England and the cross-ARC care home research collaboration.

We would also like to thank: The Care Home Care WhatsApp and Covid-19 Care platform founders; Wren Hall: Anita Astle; Royal Derby Hospital: Professor Adam Gordon, Nottingham & Nottinghamshire CCG: David Ainsworth, PerCurra at Home: Gill Heppell, Landermeads Care Home: Ros Heath, Sears Healthcare: Dr Richard Adams, The Manor Residential Home: Hitesh Chavda, NHS Mansfield & Ashfield CCG and NHS Newark & Sherwood CCG: Donna Nussey, My Home Life and National Care Forum: Professor Julienne Meyer.

The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health and Social Care.

Background

In many countries, care homes are being disproportionately affected by the COVID-19 global pandemic, with high rates of mortality (Oliver, 2020a, Comas-Herrera and Zalakin, 2020, British Geriatrics Society, 2020a). In the UK, central government guidance on how care homes should respond to COVID-19 has been inconsistent and criticised for being overly health-focused, disregarding the health and safety of the social care workforce and the conditions within which they are working (The National Care Forum, 2020).

There are approximately 1.49 million people working in adult social (long-term) care in England, most of whom are employed by the independent sector (Skills for Care, 2019). Whilst demand for care has led to significant increases in the number of jobs in the social care sector, most of these (76%) are direct care roles, fulfilled by a workforce historically referred to as 'unskilled' (Skills for Care, 2019). Regulated professionals (e.g. social workers, occupational therapists and nurses) account for only 5% of the workforce, compared with 54% of the workforce in health (NHS Digital, 2018).

Within adult social care in England, care homes account for approximately 42% of jobs (Skills for Care, 2019), caring for approximately 400,000 people (LaingBuisson, 2018), many of whom have multiple and complex needs, including need for nursing care (Gordon et al., 2014). Despite increases in the number of care jobs in nursing homes between 2009 and 2018, the number of registered nursing jobs has seen a significant decrease (down 20% since 2012). Due to population ageing and funding restrictions, older people living in care homes typically depend on staff to meet basic needs in the last year(s) of life (Gordon et al., 2014, Oliver, 2020b, Wittenberg et al., 2019, Dudman et al., 2018). These trends are associated with the ongoing escalation of responsibility and range of skills expected from undervalued and low-paid care staff (Scales et al., 2017). The need to recognise and reframe the skills and identity of social care workers has recently been recognised (All-Party Parliamentary Group on Social Care, 2019) and there is growing pressure on the government for urgent reform of the pay and working conditions to match the responsibilities and work of the sector (Hayes et al., 2019).

The lack of recognition and low pay is not limited to the UK. Globally, the long-term care sector relies on a low-paid, often non-qualified workforce to provide skilled care for vulnerable older people (e.g. Hodgkin et al., 2017, Chamberlain et al., 2019). In the UK, care home staff were one of many groups to benefit from the introduction of a national minimum wage in 1999, it was not however, sector specific and did not differentiate between the value of staff skills from other low-paid employment (Moriarty et al., 2018). This is despite evidence that care workers, as professionals, are expected to have significant skills that cover; (a) health and medicine, (b) values and philosophies of care, (c) literacy, numeracy, language and communication, (d) technology and digital, (e) employability skills and (f) body work (Hayes et al., 2019). In New Zealand, care worker pay was recently increased and is linked to qualifications and experience (Douglas, 2019). The increase has been welcomed, but workloads and duties have also expanded.

Internationally, few professional organisations exist for care home staff, notable exceptions being the North American National Association of Health Care Assistants (NAHCAC) and the Royal College of Nursing (RCN) in the UK who have membership for health care assistants who work in health and social care (Royal College of Nursing, 2020). Standardised training for new recruits in the UK is not a

mandatory requirement. The introduction of the Care Certificate, however, is anticipated to contribute to the recognition of staff skills and formalising career pathways (Schneider, 2017).

During the pandemic, there have been examples of care homes supporting each other through discussion groups and communities of practice. One such example is a national online care home community of practice, which was supported by clinicians, care managers, commissioners and academics (<https://webapp.mobileappco.org/m/COVID19CARE/>). It is a powerful example of co-working and co-production, addressing the concerns of frontline staff. Although, with greater involvement of sector representatives, the need for sector specific guidance is increasingly being addressed (The National Care Forum, 2020, British Geriatrics Society, 2020a, Public Health England, 2020a), at the start of the pandemic care homes were seeking support and guidance on challenges being faced in everyday practice. Many of these were focused on how to access personal protective equipment (PPE) and what this should comprise but there were also COVID-19 specific questions about care, and the support of families who were no longer able to visit the care homes. Care homes wanted to know how to; provide comfort and reassurance to people living with dementia without physical contact, maintain social distancing with residents who do not understand or remember why this is happening, anticipate the end of life care needs of residents, support staff and families who are grieving, and maintain communication at a distance.

This led to discussions with health and social care researchers across the National Institute for Health Research Applied Research Collaborations (ARCs) to identify implementable evidence that could complement best practice, official guidance and experiential knowledge. The aim was to produce rapid, expert, research-based reviews translated into highly usable 'Top Tips' for care homes or "rules of thumb", to guide difficult situations in everyday practice. These Top Tips are considered dynamic, living documents, that complement official guidance and are designed to be updated as new evidence/emerges throughout the pandemic.

The aim of this paper is to describe how we addressed some of the challenging practice questions emerging from the care home sector in the early stages of the COVID-19 crisis in the UK, reflecting on our expectations of the care home workforce and the implications for research and practice.

Methods

This work was undertaken in the first three months (February-April 2020) of the COVID-19 pandemic in the UK. It involved a rapid review of available policy documents and guidance, identification of care home staff generated questions that the co-authors could respond to and rapid evidence reviews on eight "top tips for tricky times" (TTTT). The agreed brief was to search for relevant peer reviewed evidence, and to draw out clear, accessible 'Top Tips' for practice. They were designed as heuristics or rules of thumb to help support staff, especially those who have less experience (International Long-Term Care Policy Network, 2020). This work was designed to complement, not replace, central government guidelines and did not include infection prevention or control (IPC), which was a rapidly developing policy focus and beyond the scope of the rapid reviews. The reviews themselves are described below (see Expert Reviews).

Drafts of the TTTT were reviewed for relevance and usefulness by frontline staff, accessed via representative forums, provider organisations and personal contacts of the team. They were asked to comment on whether the tips were helpful, which ones were relevant, who they thought would use them and what format would work best for use by care home staff.

Ethical review was not required. No primary research data was collected as part of this research. The topics for the expert reviews came from the care home workforce, meaning we adopted a co-production approach to inform the design and format of the Top Tips. In line with this, care workers' anonymised feedback on the Top Tips is summarised in the findings.

1. Expert reviews (ER)

The term 'expert review' (ER) was used to signal that the reviews were carried out by academics actively researching in care homes and social care. The following topics were identified from questions arising from care home staff and managers in a WhatsApp© group set up in the first few weeks of the COVID-19 pandemic. This was prior to the creation of the online community of practice described above (<https://webapp.mobileappco.org/m/COVID19CARE/>). The authors focused on topics they could quickly respond to, based on their current or previous research.

ER1: End of life care when staff are unsure what is best

For the majority of care home residents living with dementia it is possible to recognise their needs and support them as they approach the end of life. Much of this knowledge is transferable for people dying with COVID-19 and has been adapted for the pandemic (e.g. Fusi-Schmidhauser et al., 2020). Previous research on end of life care has identified that for a small group of residents dying with or from dementia there is uncertainty about the best ways to manage symptoms, liaise with different people involved in decision making and anticipate resource needs.

ER2: Hydration and COVID-19

During the COVID-19 pandemic, residents may be more socially isolated, so opportunities to enjoy drinks socially with friends may be reduced. As with other infections, COVID-19 may present differently in older people, with reported symptoms including fever, cough, breathlessness, loss of smell and taste, apathy, delirium and diarrhoea. Combined, these symptoms both increase the body's needs for fluids as well as making drinking more difficult, increasing dependency on care staff for regular drinks and continence support. Staff should be supported to ensure that residents drink sufficiently, and not to rely on common signs and symptoms to detect dehydration, as research has demonstrated that these are ineffective in older people, and thus should not be used (Bunn and Hooper, 2019, Volkert et al., 2019, Hooper et al., 2015, Bunn et al., 2019).

ER3: Supporting families at a distance

Early into the pandemic, care homes attempted to protect their residents from the virus by stopping visitors. This limits opportunities for communication between staff and families. Communication is likely to be organised via video-links, WhatsApp groups and chat forums via various internet platforms. However, not all families are familiar or comfortable with technology and/or may not have the bandwidth required to support such communication. Staff capacity is also stretched to the limit. This gave rise to the question of how communication and information sharing might be best supported between family, residents and staff?

ER4: Supporting residents with dementia to stay in touch with families using video-calls

As well as impacting on information sharing (ER3), this separation from families and friends outside the home is likely to be a source of distress, loneliness and added confusion to many residents. It is

painful for their family, adding to a sense of fear and powerlessness to help. Technological solutions such as video-calling have been recommended (Adult Social Care Directorate, 2020, British Geriatrics Society, 2020a) but some care homes have little experience of this and do not know the best way to do this, especially for those residents with dementia. The review drew on available evidence from research specifically with people living with dementia or in care homes.

ER5: Supporting residents who do not understand self-isolation and social distancing

Cognitive impairment, including as a consequence of delirium from COVID-19 infection, affects the ability of residents to remember or understand the need to self-isolate in their room and maintain a distance from others. COVID-19 has reduced the number of safe areas within care homes for residents to walk. For care home residents who walk with purpose, non-pharmacological interventions are recommended and physical restraint should not be used. The capacity of care home staff to provide non-pharmacological interventions may be impacted by COVID-19 infection control priorities and reduced staff to resident ratios.

ER6: Using doll therapy to comfort people with dementia

The pandemic has meant that physical contact is greatly reduced for people living in care homes. This includes contact between residents and family members, residents and staff and between residents. Alternatives to human physical contact such as soft toys and dolls have been suggested as ways to provide comfort and reduce distress (Mitchell et al., 2016, Ng et al., 2017, Shin, 2015). Pet therapy and animal robots were discounted as impractical at this time. The use of soft toys and dolls maybe an additional resource for care homes to draw on during this pandemic, especially for those residents living with dementia.

ER7: Using music to provide comfort and reassurance.

There is evidence that music therapy can have a beneficial effect for care home residents with dementia, reducing depression, anxiety and behavioural manifestations of need. There are a variety of approaches to music provision – including music therapy, music listening and general music-based interventions (Raglio et al., 2015). Active music therapy that involves a therapist coming into a home and playing live music is not advisable because of COVID-19. But individualised music may still provide comfort and reassurance for care home residents, including those living with advanced dementia.

ER8: Supporting staff following deaths in care homes.

We don't have a full analysis of COVID-19 related deaths in care homes, but we do know that care homes are experiencing multiple deaths. Reference to deaths of residents in the current guidance primarily refer to infection control. The grief that care workers may experience and which may impact on their ability to deliver care is not acknowledged or addressed. Given evidence about the impact of grief on staff when people they have cared for die, it was important to address this and to draw on evidence available to suggest what support staff might need to deal with their grief.

2. Review of official COVID-19 guidance for care homes

To complement the review work and identify the depth and breadth of guidance being issued by central and local governments and the care regulator, we carried out a rapid, desk-based review of the content of official government and expert COVID-19 guidance documents. Only documents

providing guidance to care home staff, managers, residents and/or visitors were included; document contents were therefore screened for references to care homes. The analysis included all relevant publications up to 30/04/2020, reflecting when this work was undertaken. Data were coded to extract and categorise COVID-19-related requirements for care home staff and care home managers. Specifically, we were interested in identifying new or additional requirements of care homes, relating to the COVID-19 pandemic.

Findings

Review 1: Expert Reviews (ER)

The first wave of eight expert reviews were rapidly conducted in April 2020. Table 1 outlines the authors of each review, the methods used, evidence reviewed and gaps in evidence identified for each one. The underpinning references for the evidence drawn upon to inform the 'Top Tips' for care home staff are provided in the Supplementary Materials.

The guiding principles of the reviews were that: we were producing "rules of thumb" or heuristics to help support staff, that each 'Top Tip' had a basis in research and that they were a response to care home staff questions.

[TABLE 1 HERE]

Assumptions made

For the TTTT to create easily digestible, rules of thumb or heuristics for care home staff, assumptions often had to be made. For example, review four on supporting care home residents with dementia to communicate with their families through video-calls, had to assume that: there are tablets, smartphones or computers available for video communication; that care staff are able to support residents to communicate with their families remotely (for example, that they have sufficient time, and that infection control procedures in place do not preclude this contact between care staff and residents); that there is suitable internet/wi-fi connection at the care home and within the care home if residents are remaining in their rooms; that residents have family or friends who are also internet connected and have a device that can use video. These things may not be in place in practice. Early drafts included statements about these assumptions, links to guidance and supplementary sources of evidence. However, for the TTTT to be concise, the decision was made to remove such supplementary information.

Main messages and gaps in evidence

ER1: End of life care when staff are unsure what is best

This ER drew on earlier work, which identified that there will always be a small group of residents where end of life care is characterised by uncertainty. The learning from this work was very relevant for people with COVID-19. The uncertainty about the significance (and absence) of certain symptoms, who leads on decision making and how to ensure adequate resources were in place characterise the daily experience of care home staff. The Top Tips gave permission for care home staff and the health care professionals they worked with to frame these issues as those without

immediate solutions and offered ways to organise their thinking. The feedback from care home staff indicated they valued the recognition that it had to be a negotiated experience.

Future work needs to develop interventions that can accommodate situations when it is not clear what treatment is the 'right' treatment, who should do what and when, and where care should be provided and by whom. As a measure of effectiveness, the ability to "hold" uncertainty between the different players and organisations when providing end of life care needs to be operationalised. Articulating how uncertainty is expressed and experienced in working relationships and decision making at the resident and service level of care in care homes demonstrates how service care trajectory uncertainties can be managed. There is a need for palliative care interventions that can build in strategies that foster trust and patterns of working and communicating that cross organisational boundaries and build in service flexibility and review at times of crisis.

ER2: Hydration and COVID-19

Older people, particularly those living in care homes, are at increased risk of low-intake dehydration due to drinking insufficiently to replace obligatory fluid losses (Bunn and Hooper, 2019). Whilst physiological processes of ageing increase dehydration risk, the main cause is drinking insufficiently. Current guidelines for adult daily fluid intakes (all ages) are 2L/day for men and 1.6L/day for women (with an additional 20% of fluid from foods) (Volkert et al., 2019). Many older people do not drink these amounts, describing lack of thirst, difficulties with access (fetching, carrying, reaching, swallowing drinks), concerns about continence and remembering to drink. Routine tests for dehydration (such as dry mouth or skin, and/or dark-coloured urine) are unreliable in older people living in care homes (Bunn and Hooper, 2019). Therefore, the focus of care should be on prevention, and offering drinks to all residents regularly is recognised as the best way to prevent dehydration.

The Top Tips focus on supporting care home staff to be creative in how they can offer drinks to residents by, for example, encouraging staff to find out what drinks residents prefer, and the type of cup they like. Providing drinks as part of social activities and interactions, together with any help that is needed, are central to ensuring that residents drink well, in a congenial environment. Offering a wide selection of drinks, including fruit juices, milky drinks as well as tea and coffee and foods such as soup that have a high fluid content, is important, as well as ensuring that all residents are offered beverages during drinks rounds and with medication and meals. A web-based resource supporting hydration care for older adults, developed collaboratively with care home staff from eleven care homes in Norfolk and Suffolk, UK, is available (DrinKit resources: <https://www.uea.ac.uk/web/groups-and-centres/uea-hydrate-group/drinkit>).

ER3: Supporting families at a distance

The fact that families were not allowed to visit residents in care homes during COVID-19 prompted the question of 'how to best support families who are now caring at a distance'. Peer-reviewed literature on 'distance caregiving' focuses primarily on the logistics of having to coordinate care from a distance for people living at home, for example the co-ordination of shopping, banking and arranging medical appointments (Blackstone et al., 2019). This relies on local networks of friends, neighbours and allied health and social care practitioners (Franke et al., 2019) but has not been applied to care homes.

Whilst care home staff do have a great deal of communication with residents' families, there has not been a need to research the notion of 'extending care' to settings beyond the care home, hence the lack of studies on this topic. However, transferable learning is offered by research in contexts such as hospices, intensive care units and palliative care (Bélanger et al., 2017, Kynoch et al., 2016, Petros and John, 2019, Schulman-Green and Feder, 2018, Gilissen et al., 2018, Wittenberg et al., 2017, Adams et al., 2017) who employ trained staff to offer counselling, bereavement counselling and spiritual care. This is not currently part of the portfolio of care-home services, although care home staff often do develop close relationships with residents and families and offer consolation and emotional support.

COVID-19 highlighted once again that many care homes are woefully under-resourced. The expectation that staff 'support families to care at a distance' is just one more ask, and task, yet they try their utmost to keep communication going and families updated. The tips provided are intended to support staff to cope by structuring communications.

ER4: supporting video-calls during the pandemic

Reviewing the evidence even taking the assumptions above, reveals that there is very little research that has investigated the experience of older care home residents with dementia using tablets or screens for video calls. There is a little research which indicates that people with dementia may find the additional visual input of body language and facial expression on a video call is helpful in taking part in an interaction (Boman et al., 2014, Meiland et al., 2017, Moyle et al., 2020a) and that such calls can help to reduce isolation and loneliness (Guo et al., 2016). There is some experience that colour contrasts may be perceived differently, and that the light and sound in the environment should be managed to make the screen and the sound as clear as possible for the resident (Boman et al., 2012). Use of the loud-speaker function is helpful. It is clear however that support from staff is needed by most residents (Guo et al., 2016, Evans et al., 2017, Moyle et al., 2020b). Protective covers can make it easier to grip devices, and also to clean them for infection control. The Top Tips focus on these evidenced-based, practical considerations when trying to support families and residents to stay in touch at a distance.

However, there is little research that offers evidence for supporting successful interaction on video enabled devices. Care home staff attempting to meet the needs of care home residents for social contact with important people in their lives, and for continuity of relationships, will be learning from experience, developing know-how, skills and expertise. They are likely to bear the expectations of families for meaningful contact with their relative and also the emotional cost of witnessing the interactions, as highlighted in ER3.

ER5: Supporting residents who do not understand self-isolation and social distancing

There was some evidence for planning and pre-empting residents' needs. Research has been largely descriptive with some examples of how to accommodate or adapt the behaviour to be manageable within the care home setting (Rapaport et al., 2018, Husebo et al., 2011, MacAndrew et al., 2017, Edvardsson et al., 2012). Supporting personal interests and providing occupation have been shown to reduce agitation, which may include walking with purpose (O'Neil et al., 2011, Travers et al., 2016). There was evidence that pre-emptive exercise and walking with residents could help reduce difficult walking behaviours (Robinson et al., 2007). However, in current circumstances, staff may not have the capacity to support walking and occupation. There was mixed evidence for environmental

adaptations, such as the use of mats and covering door handles to discourage entry or exit of rooms (Neubauer et al., 2018).

Research for practical, person-centred approaches to manage immediate situations, such as helping a resident leave someone else's room, was limited. Common, in-the-moment strategies used by care home and hospital staff were reported in qualitative studies, however their effectiveness was inconsistent (Backhouse et al., 2016, Handley et al., 2019). One hospital-based study on the impact of staff communication skills on people living with dementia's agreement to the completion of care tasks suggested an evidence-based structure for phrases that could be used to encourage residents to move to safe areas (Harwood et al., 2018). No research investigated when restraint could be ethically defensible or which type/s would be least restrictive. However, an evidence-based guideline to reduce restraint use in home care settings has been developed in the Netherlands (Scheepmans et al., 2020).

ER6: Using therapy dolls to comfort people with dementia

Evidence suggests that where doll therapy has been introduced in care homes it can help to alleviate behavioural and emotional symptoms. Doll therapy can reduce distress, agitation, wandering (walking with purpose) and increase engagement, communication, well-being, mood and appetite (Mitchell et al., 2016, Ng et al., 2017, Shin, 2015). Dolls can provide companionship, attachment, ownership and inclusion (Alander et al., 2015). The introduction of dolls can be argued to be part of person-centred care, whilst recognising the importance of knowing personal history, traumatic events and parenting style (Pezzati et al., 2014). Some guidelines have been suggested; including using life-like dolls with open eyes (Alander et al., 2015). Dolls were often preferred to soft toys, the importance of staff interaction and only one paper addressed issues around decontamination (Subramanian et al., 2014).

However, research suggests that there is a need for more studies. A recent pilot randomised control trial (Moyle et al., 2019) found that whilst there was an increase in pleasure for those having doll therapy, there was not a significant reduction in anxiety, agitation or aggression when compared to usual care. Limitations include confusion over ownership of the doll and uncertainty about issues relating to autonomy (Mackenzie et al., 2006, Mitchell et al., 2016). Some authors also suggest that the theoretical basis of doll therapy is poorly understood, ethically questionable and risks infantilising residents (Alander et al., 2015, Mitchell and O'Donnell, 2013, Pezzati et al., 2014).

ER7: Using music to provide comfort and reassurance.

Recent reviews of sensory and arts-based interventions for people living with dementia in care homes have highlighted the importance of activities that enable the development of moments of connection for residents (Bunn et al., 2018, Cousins et al., 2019). This might be between residents and staff or family members, or by invoking a connection with past memories. Music has the potential to create those moments of connection. Whilst most research has looked at active music therapy (usually delivered by a trained music therapist) there are some studies on music listening. Music listening has the advantage that it does not rely on a trained music therapist. Two recent reviews have looked at the difference between active music therapy and music listening (Leggieri et al., 2019, Tsoi et al., 2018). Both found that music listening could be effective, but it was important that music was individualised. Familiar music may have more positive effects on people with

dementia because it can invoke autobiographical memories (Leggieri et al., 2019). A few studies have looked at the use of MP3 players to provide individualised music but this can be costly and requires support from staff or volunteers (Murphy et al., 2018, Hebert et al., 2018).

Review 8: Supporting staff following deaths in care homes.

There is very little research that has investigated how care home staff experience the death of care home residents and to what extent they are prepared for this experience and supported in their bereavement. Indeed, staff grief may be overlooked (Tsui et al., 2019) leading to what is known as disenfranchised grief. What evidence exists suggests there is a need to prepare staff via better education about bereavement (Österlind et al., 2011) and a need to have bereavement support mechanisms in place (Carton and Hupcey, 2014, Boerner et al., 2015). Some evidence suggests that grief over residents' deaths play an overlooked role in direct care worker burnout (Boerner et al., 2017). Key recommendations for support include peer debriefing and support (Chen et al., 2019, Chen et al., 2018, Vis et al., 2016). Some interventions had been developed such as peer-led debriefing intervention (Vis et al., 2016), but overall few interventions have been developed or rigorously tested.

There is little research that offers evidence for supporting staff who are experiencing multiple deaths although the cumulative burden of ongoing grief is recognised (Marcella and Kelley, 2015). Here we sought transferable learning from existing evidence about staff dealing with large scale deaths in disasters or in other pandemics. Because in such situations, everyone is affected, it can be more difficult to access or provide support. Some staff might experience 'compassion fatigue' which is characterised by emotional and physical exhaustion leading to a diminished ability to empathise or feel compassion for others (Tellie et al., 2019).

The Top Tips

The Top Tips generated from these reviews can be found in the [Supplementary Materials](#). The Tips are dynamic, living documents that will be edited and added to as new evidence emerges throughout the pandemic. These are version one, based on this initial piece of work. Readers can access the most recent version(s) online: <https://arc-eoe.nihr.ac.uk/covid-19-projects-innovations-and-information/covid-19-resources-training-information/top-tips>.

The Top Tips are a product of the eight expert reviews and feedback from seven frontline care home staff from different care homes and two group discussions in virtual, online communities of care home staff. In all cases, the feedback was anonymous and gathered via contacts of members of the research team, via known care workers, the National Care Forum (a provider representative organisation in the UK) and a care home provider, with a chain of 30 care homes. By necessity, feedback and responses were brief and we were not able to code which care worker said what, as we would in an interview or focus group. The priority was to gather feedback to inform the content and format of the Top Tips and facilitate their use in homes.

In general, the feedback was very positive:

"I feel they may be helpful to give people ideas on what they could do in these times to best support residents and also meet their emotional needs"

"I would like to see this as a carer, as I want reassurance in these scary times"

Some reviews stimulated more debate than others (e.g. ER6 – Dolls). Care workers welcomed the Top Tips because they felt it offered staff reassurance about an element of practice that had sometimes been questioned or was seen as controversial. In other cases (e.g. ER5 – when residents do not understand social distancing), the feedback really highlighted the need to walk a line between being helpful ‘in the moment’ without subverting the principles of person-centred care and knowing the resident well:

“Do staff really need examples of what to say?”

However, there was also a recognition that these might be ideal for new or junior staff and that staff were working under unprecedented pressures, in which easily digestible tips such as these might be particularly welcome. For example, referring to ER8:

“It tells me that it’s ok not to be ok...I need to know that I can cry, I’m not being unprofessional, I’m simply having a human reaction...”

When asked about how best to present these tips, staff agreed that posters with concise wording would work well, as these can easily be updated as new evidence emerges. The next stage of the work will be to track how and when they are used.

Review two: policy documents/official guidance

The complementary rapid-review of government and expert guidance documents emphasised the magnitude of additional requirements for care home staff and managers during the COVID-19 pandemic. The final sample included 18 guidance documents (Adult Social Care Directorate, 2020, Public Health England, 2020b, Public Health England, 2020i, Public Health England, 2020h, Department of Health and Social Care, 2020b, Care Quality Commission, 2020, Department of Health and Social Care, 2020a, Department of Health and Social Care, 2020c, GOV.UK, 2020, British Geriatrics Society, 2020a, British Geriatrics Society, 2020b, Public Health England, 2020g, Public Health England, 2020f, Public Health England, 2020e, Public Health England, 2020c, Department of Health and Social Care, 2020d, Public Health England, 2020j, Public Health England, 2020a, Public Health England, 2020d); with the majority (N=9) produced by Public Health England. Guidance issued by the Care Quality Commission, the British Geriatrics Society, and Adult Social Care Directorate were also analysed.

Guidance included measures on social distancing, shielding, isolation and cohorting – some applicable to all residents, and others concerning those with suspected or confirmed COVID-19. Daily reporting of occupancy and guidance on accepting hospital discharges of people potentially with COVID-19 were also introduced, along with infection, prevention and control (IPC) measures and procurement and use of Personal Protective Equipment (PPE). Care home managers were also required to individually risk assess each staff member. Some requirements outlined in government and expert guidance were not novel and were already in place before the pandemic. However, even in these cases, COVID-19 introduced new challenges to routine tasks. For example, GP consultations for clinical management of residents at the end of life no longer involved GP visits to the care home, and assessing appropriateness for hospitalisation had to take into account risk of contracting COVID in hospital (see Figures 1 and 2 for greater detail).

The large number of guidance documents and multiple specific requirements continues to change rapidly. For example, at the time of writing, government guidance on ‘Admission and care of

residents during COVID-19 incident in a care home' (Adult Social Care Directorate, 2020) has undergone two updates since first publication. This risks information overload for an already overburdened workforce.

Care homes, especially those without onsite nursing have particular challenges in their ability to implement the new requirements. For example even if equipment is available, access to health care professionals is needed to interpret residents' vital signs and pulse oximetry, and support delivery of treatments involving oxygen, subcutaneous fluids and antibiotics, (British Geriatrics Society, 2020a).

There have also been instances where government advice has lacked the specificity of expert advice. For example, expert advice emphasised the importance of care home staff assessing for and recognising non-respiratory COVID-19 symptoms and subtle signs of deterioration among residents (British Geriatrics Society, 2020a), which was not mentioned in government advice. This guidance also stressed that PPE -related requirements should be the same in care homes, as in hospitals, while government guidance on PPE presented different requirements for primary, outpatient, community and social care sectors (Public Health England, 2020j). Additionally, existing government guidance has not yet provided specific advice on supporting care home residents living with dementia, despite an estimated 80% of care home residents having significant memory problems (Alzheimer's Society, 2013). Guidance from the British Geriatrics Society (British Geriatrics Society, 2020b), however, emphasised additional challenges when supporting people with dementia, who, for example, may not be able to follow infection control or cohorting measures.

Figure 1. COVID-19 related requirements for Care Home staff

Figure 2. COVID-19 related requirements for Care Home managers

Discussion

This paper has presented the findings from a project that aimed to use research evidence to respond to the priorities and concerns of care home staff in the first few months of the COVID-19 outbreak., It also provided a rapid review of policy guidance at the time (February-April 2020). Our findings highlight the considerable expectations of the skills and aptitudes of front-line care home staff and dearth of context specific empirical evidence and guidance. These findings support the conclusions of a recent all party parliamentary group review on this subject, which called for greater recognition of these skills through better pay and working conditions (Hayes et al., 2019).

Care home staff have been working dynamically, under considerable pressure, to translate central government policy into practice during the pandemic. Understandably, care home managers and staff have raised many questions and concerns, touching on a wide range of topics and academic disciplines (see Box 1), as they adapt to the pandemic and the expectations being placed upon them. Their questions have highlighted the complex nature of direct care in this frail and particularly vulnerable population. Indeed, to provide evidence-based answers and easily actionable tips, a multi-disciplinary team of academics, working in care homes research, undertook eight rapid, expert reviews (ERs). These ERs shed light on the multidisciplinary nature of care homes' research and practice and the paucity of research and guidance helping care staff solve direct care issues *in the moment*. Care homes know what they should or should not do (e.g. ensure residents socially

distance but do not use restraint) but the questions they want answers to is 'how?'. This was often where the biggest gaps in research evidence lay.

Box 1: Skills and aptitudes of care workers

Taken from Hayes et al (2019)

1. Health and Medicine (ER1 & 2)
2. Values and Philosophies of Care (ER5-7)
3. Literacy, Numeracy, Language and Communication (ER4, 3 & 5)
4. Technology and Digital (ER4)
5. Employability Skills (ER8)
6. Body Work (ER1)

Care home staff are a low-paid and undervalued workforce (Scales et al., 2017, Hussein and Manthorpe, 2012) yet they are regularly being asked to respond to complex, multidisciplinary issues (Gordon et al., 2014, Gordon et al., 2018). The COVID-19 pandemic has intensified these issues and paradoxically, reduced the face-to-face support they would normally receive from external healthcare providers (British Geriatrics Society, 2020a). The global pandemic has raised awareness of the important, skilled work carried out by care home staff and care homes' role within health and social care systems (Oliver, 2020a, Pollock et al., 2020). Our work has identified how few opportunities there are for the sector to identify priorities for research and comment on the relevance of guidance for the long-term care setting.

With care home workers now classed as 'essential workers' and with attempts to recognise the sector in line with health service colleagues, there appears, at last, to be recognition of their work. It remains to be seen whether this will be sustained beyond the current crisis and progress from a reliance on moral motivations to promote career pathways and professionalisation that value this workforce.

Conclusion

Care home research needs to be multidisciplinary, and trying to situate research in either health or social care is not helpful. We have demonstrated how involving care homes in setting the research agenda ensures that their priorities are addressed. A collaborative approach changes the focus of research from what 'ought to be done' in care home to 'how it can best be done' with care homes. Research that prepares and involves staff in the process can recognise and value their skills of and lead to longer term partnership working (Fossey et al., 2020).

There are initiatives that have supported and promoted collaborative approaches to research with care homes. My Home Life (<http://myhomelife.org.uk>) has advocated the sharing, development and co-creation of evidence-based best practice since 2006. The NIHR ENRICH resource (<https://enrich.nihr.ac.uk/>) also supports researchers, care homes and the care home community to work together by providing guidance for research best practice. However, this work has exposed how much more needs to be done to build research programmes that reflect the needs of residents

Producing Top Tips for care home staff during COVID19

and staff. The irony of this crisis is that care workers, frequently described in policy terms as unskilled, have demonstrated new ways of working and shared problem solving that can directly inform how evidence is used and research commissioned.

REFERENCES

- ADAMS, A., MANNIX, T. & HARRINGTON, A. 2017. Nurses' communication with families in the intensive care unit—a literature review. *Nursing in critical care*, 22(2), 70-80. DOI: <https://doi.org/10.1111/nicc.12141>
- ADULT SOCIAL CARE DIRECTORATE. 2020. *Admission and Care of Residents during COVID-19 Incident in a Care Home. Version 1. Published 2 April 2020* [Online]. Available: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/880274/Admission_and_Care_of_Residents_during_COVID-19_Incident_in_a_Care_Home.pdf [Accessed 30 April 2020].
- ALANDER, H., PRESCOTT, T. & JAMES, I. A. 2015. Older adults' views and experiences of doll therapy in residential care homes. *Dementia*, 14(5), 574-588. DOI: <https://doi.org/10.1177/1471301213503643>
- ALL-PARTY PARLIAMENTARY GROUP ON SOCIAL CARE. 2019. Social Care Elevation, Registration & Standardisation: The Professionalisation of Social Care Workers An Inquiry Report. Available at: www.appgsocialcare.org.uk
- ALZHEIMER'S SOCIETY 2013. Low expectations: attitudes on choice, care and community for people with dementia in care homes. Alzheimer's Society London.
- BACKHOUSE, T., KILLET, A., PENHALE, B. & GRAY, R. 2016. The use of non-pharmacological interventions for dementia behaviours in care homes: findings from four in-depth, ethnographic case studies. *Age and ageing*, 45(6), 856-863. DOI: <https://doi.org/10.1093/ageing/afw136>
- BÉLANGER, L., BOURBONNAIS, A., BERNIER, R. & BENOIT, M. 2017. Communication between nurses and family caregivers of hospitalised older persons: a literature review. *Journal of clinical nursing*, 26(5-6), 609-619. DOI: <https://doi.org/10.1111/jocn.13516>
- BLACKSTONE, E., LIPSON, A. R. & DOUGLAS, S. L. 2019. Closer: A videoconference intervention for distance caregivers of cancer patients. *Research in nursing & health*, 42(4), 256-263. DOI: <https://doi.org/10.1002/nur.21952>
- BOERNER, K., BURACK, O. R., JOPP, D. S. & MOCK, S. E. 2015. Grief after patient death: Direct care staff in nursing homes and homecare. *Journal of pain and symptom management*, 49(2), 214-222. DOI: <https://doi.org/10.1016/j.jpainsymman.2014.05.023>
- BOERNER, K., GLEASON, H. & JOPP, D. S. 2017. Burnout after patient death: challenges for direct care workers. *Journal of pain and symptom management*, 54(3), 317-325. DOI: <https://doi.org/10.1016/j.jpainsymman.2017.06.006>
- BOMAN, I.-L., NYGÅRD, L. & ROSENBERG, L. 2014. Users' and professionals' contributions in the process of designing an easy-to-use videophone for people with dementia. *Disability and Rehabilitation: Assistive Technology*, 9(2), 164-172. DOI: <https://doi.org/10.3109/17483107.2013.769124>
- BOMAN, I.-L., ROSENBERG, L., LUNDBERG, S. & NYGÅRD, L. 2012. First steps in designing a videophone for people with dementia: identification of users' potentials and the requirements of communication technology. *Disability and Rehabilitation: Assistive Technology*, 7(5), 356-363. DOI: <https://doi.org/10.3109/17483107.2011.635750>
- BRITISH GERIATRICS SOCIETY 2020a. Managing the COVID-19 pandemic in care homes for older people: Good practice guide. Date Published: 25 March 2020, Last updated: 14 April 2020
- BRITISH GERIATRICS SOCIETY 2020b. COVID-19: Dementia and cognitive impairment. Good practice guide. Date Published: 07 April 2020, Last updated: 07 April 2020. . British Geriatrics Society. Available at: <https://www.bgs.org.uk/resources/covid-19-dementia-and-cognitive-impairment>
- BUNN, D., JIMOH, O., KARROUZE, I., WYATT, K. & HOOPER, L. 2019. Effective hydration care for older people living in care homes. *Nursing Times*, 115(9), 54-58.
- BUNN, D. K. & HOOPER, L. 2019. Signs and Symptoms of Low-Intake Dehydration Do Not Work in Older Care Home Residents—DRIE Diagnostic Accuracy Study. *Journal of the American*

- Medical Directors Association*, 20(8), 963-970. DOI:
<https://doi.org/10.1016/j.jamda.2019.01.122>
- BUNN, F., LYNCH, J., GOODMAN, C., SHARPE, R., WALSHE, C., PRESTON, N. & FROGGATT, K. 2018. Improving living and dying for people with advanced dementia living in care homes: a realist review of Namaste care and other multisensory interventions. *BMC Geriatrics*, 18(1), 303. DOI: <https://doi.org/10.1186/s12877-018-0995-9>
- CARE QUALITY COMMISSION. 2020. Information for adult social care services during the coronavirus (COVID-19) outbreak. Last updated: 24 April 2020 Available at:
<https://www.cqc.org.uk/guidance-providers/adult-social-care/information-adult-social-care-services-during-coronavirus-outbreak>
- CARTON, E. R. & HUPCEY, J. E. 2014. The forgotten mourners: addressing health care provider grief— a systematic review. *Journal of Hospice & Palliative Nursing*, 16(5), 291-303. DOI:
<http://doi.org/10.1097/NJH.0000000000000067>
- CHAMBERLAIN, S. A., HOBEN, M., SQUIRES, J. E., CUMMINGS, G. G., NORTON, P. & ESTABROOKS, C. A. 2019. Who Is (Still) Looking After Mom and Dad? Few Improvements in Care Aides' Quality-of-Work Life. *Canadian Journal on Aging/La Revue canadienne du vieillissement*, 38(1), 35-50. DOI: <https://doi.org/10.1017/S0714980818000338>
- CHEN, C., CHOW, A. Y. & TANG, S. 2018. Bereavement process of professional caregivers after deaths of their patients: A meta-ethnographic synthesis of qualitative studies and an integrated model. *International journal of nursing studies*, 88(1), 104-113. DOI:
<https://doi.org/10.1016/j.ijnurstu.2018.08.010>
- CHEN, C., CHOW, A. Y. & TANG, S. 2019. Professional caregivers' bereavement after patients' deaths: A scoping review of quantitative studies. *Death studies*, 43(8), 500-508. DOI:
<https://doi.org/10.1080/07481187.2018.1488775>
- COMAS-HERRERA, A. & ZALAKIN, J. 2020. Mortality associated with COVID-19 outbreaks in care homes: early international evidence - Resources to support community and institutional Long-Term Care responses to COVID-19. International Long-Term Care Policy Network. Available at: <https://ltccovid.org/2020/04/12/mortality-associated-with-covid-19-outbreaks-in-care-homes-early-international-evidence/>
- COUSINS, E., TISCHLER, V., GARABEDIAN, C. & DENING, T. 2019. Principles and features to define and describe arts interventions for people with dementia: a qualitative realist study. *Arts & health*, 11(3), 202-218. DOI: <https://doi.org/10.1080/17533015.2018.1490787>
- DEPARTMENT OF HEALTH AND SOCIAL CARE. 2020a. COVID-19: Our Action Plan for Adult Social Care. Version 1.0, Published 15 April 2020 Available at:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/879639/covid-19-adult-social-care-action-plan.pdf
- DEPARTMENT OF HEALTH AND SOCIAL CARE. 2020b. Guidance: Responding to COVID-19: the ethical framework for adult social care. Published 19 March 2020. Available at:
<https://www.gov.uk/government/publications/covid-19-ethical-framework-for-adult-social-care/responding-to-covid-19-the-ethical-framework-for-adult-social-care>
- DEPARTMENT OF HEALTH AND SOCIAL CARE. 2020c. Health Technical Memorandum 01-04: Decontamination of linen for health and social care. Social care Available at:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/527545/Social_care.pdf
- DEPARTMENT OF HEALTH AND SOCIAL CARE. 2020d. HS Commissioning Board Capacity Tracker. Available at: <https://carehomes.ncsu.nhs.uk/>
- DOUGLAS, J. A. R., K. 2019. The value of care. Understanding the impact of the 2017 pay equity settlement on the residential aged care, hom nad community care and disability support sectors. Auckland, New Zealand: New Zealand Work Research Institute. Available at:
https://workresearch.aut.ac.nz/_data/assets/pdf_file/0019/258130/Pay-Equity-Report_Digital_final.pdf

- DUDMAN, J., MEYER, J., HOLMAN, C. & MOYLE, W. 2018. Recognition of the complexity facing residential care homes: a practitioner inquiry. *Primary health care research & development*, 19(6), 584-590. DOI: <https://doi.org/10.1017/S1463423618000105>
- EDVARDSSON, D., SANDMAN, P. O. & RASMUSSEN, B. 2012. Forecasting the ward climate: a study from a dementia care unit. *Journal of Clinical Nursing*, 21(7-8), 1136-114. DOI: <https://doi.org/10.1111/j.1365-2702.2011.03720.x>
- EVANS, S., BRAY, J. & EVANS, S. 2017. The iPad project: introducing iPads into care homes in the UK to support digital inclusion. *Gerontechnology*, 16(2), 91-100.
- FOSSEY, J., GARROD, L., LAWRENCE, V., TESTAD, I., STAFFORD, J. & MURRAY, J. 2020. "We should see her like part of the team": an investigation into care home staff's experiences of being part of an RCT of a complex psychosocial intervention. *Aging & Mental Health*, 24(1), 178-185. DOI: <https://doi.org/10.1080/13607863.2018.1525603>
- FRANKE, A., KRAMER, B., JANN, P. M., VAN HOLTEN, K., ZENTGRAF, A., OTTO, U. & BISCHOFBERGER, I. 2019. Aktuelle Befunde zu „distance caregiving“. *Zeitschrift für Gerontologie und Geriatrie*, 52(6), 521-528. DOI: <https://doi.org/10.1007/s00391-019-01596-2>
- FUSI-SCHMIDHAUSER, T., PRESTON, N. J., KELLER, N. & GAMONDI, C. 2020. Conservative management of Covid-19 patients—emergency palliative care in action. *Journal of Pain and Symptom Management*. DOI: <https://doi.org/10.1016/j.jpainsymman.2020.03.030>
- GILISSEN, J., PIVODIC, L., GASTMANS, C., VANDER STICHELE, R., DELIENS, L., BREUER, E. & VAN DEN BLOCK, L. 2018. How to achieve the desired outcomes of advance care planning in nursing homes: a theory of change. *BMC geriatrics*, 18(1), 47. DOI: <https://doi.org/10.1186/s12877-018-0723-5>
- GORDON, A. L., FRANKLIN, M., BRADSHAW, L., LOGAN, P., ELLIOTT, R. & GLADMAN, J. R. 2014. Health status of UK care home residents: a cohort study. *Age and ageing*, 43(1), 97-103. DOI: <https://doi.org/10.1093/ageing/aft077>
- GORDON, A. L., GOODMAN, C., DAVIES, S. L., DENING, T., GAGE, H., MEYER, J., SCHNEIDER, J., BELL, B., JORDAN, J., MARTIN, F. C., ILIFFE, S., BOWMAN, C., GLADMAN, J. R. F., VICTOR, C., MAYRHOFER, A., HANDLEY, M. & ZUBAIR, M. 2018. Optimal healthcare delivery to care homes in the UK: a realist evaluation of what supports effective working to improve healthcare outcomes. *Age and Ageing*, 47(4), 595-603. DOI: <http://doi.org/10.1093/ageing/afx195>
- GOV.UK. 2020. COVID-19 Hospital Discharge Service Requirements. Published 19 March 2020 Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/880288/COVID-19_hospital_discharge_service_requirements.pdf
- GUO, Q., CANN, B., MCCLEMENT, S., THOMPSON, G. & CHOCHINOV, H. M. 2016. Keep in touch (KIT): perspectives on introducing internet-based communication and information technologies in palliative care. *BMC palliative care*, 15(1), 66. DOI: <https://doi.org/10.1186/s12904-016-0140-5>
- HANDLEY, M., BUNN, F. & GOODMAN, C. 2019. Supporting general hospital staff to provide dementia sensitive care: A realist evaluation. *International journal of nursing studies*, 96(1), 61-71. DOI: <https://doi.org/10.1016/j.ijnurstu.2018.10.004>
- HARWOOD, R. H., O'BRIEN, R., GOLDBERG, S. E., ALLWOOD, R., PILNICK, A., BEEKE, S., THOMSON, L., MURRAY, M., PARRY, R. & KEARNEY, F. 2018. A staff training intervention to improve communication between people living with dementia and health-care professionals in hospital: the VOICE mixed-methods development and evaluation study. *Health Services and Delivery Research*, 6(41). DOI: <http://doi.org/10.3310/hsdr06410>
- HAYES, L., JOHNSON, E. & TARRANT, A. 2019. Professionalisation at work in adult social care. Available at: <https://publications.parliament.uk/pa/ld201719/ldselect/ldconaf/392/39>

- HEBERT, C. A., HANCOCK, K. & MCCONNELL, E. S. 2018. Implementation of Individualized Music in Long-Term Care: Application of the PARIHS Framework. *Journal of gerontological nursing*, 44(8), 29-38. DOI: <https://doi.org/10.3928/00989134-20180626-01>
- HODGKIN, S., WARBURTON, J., SAVY, P. & MOORE, M. 2017. Workforce crisis in residential aged care: insights from rural, older workers. *Australian Journal of Public Administration*, 76(1), 93-105. DOI: <https://doi.org/10.1111/1467-8500.12204>
- HOOPER, L., ABDELHAMID, A., ATTREED, N. J., CAMPBELL, W. W., CHANNELL, A. M., CHASSAGNE, P., CULP, K. R., FLETCHER, S. J., FORTES, M. B. & FULLER, N. 2015. Clinical symptoms, signs and tests for identification of impending and current water-loss dehydration in older people. *Cochrane Database of Systematic Reviews*, (4). DOI: <https://doi.org/10.1002/14651858.CD009647.pub2>
- HUSEBO, B. S., BALLARD, C., SANDVIK, R., NILSEN, O. B. & AARSLAND, D. 2011. Efficacy of treating pain to reduce behavioural disturbances in residents of nursing homes with dementia: cluster randomised clinical trial. *BMJ*, 343(1), d4065. DOI: <https://doi.org/10.1136/bmj.d4065>
- HUSSEIN, S. & MANTHORPE, J. 2012. Structural marginalisation among the long-term care workforce in England: evidence from mixed-effect models of national pay data. *Ageing and Society*, 34(1), 21-41. DOI: <http://doi.org/10.1017/S0144686X12000785>
- INTERNATIONAL LONG-TERM CARE POLICY NETWORK 2020. Video and slides for 1st LTCcovid webinar on: International responses to COVID-19 in care homes (18 May). Available at: <https://ltccovid.org/2020/05/22/video-and-slides-for-1st-ltccovid-webinar-on-international-responses-to-covid-19-in-care-homes-18-may/>
- KYNOCH, K., CHANG, A., COYER, F. & MCARDLE, A. 2016. The effectiveness of interventions to meet family needs of critically ill patients in an adult intensive care unit: a systematic review update. *JBI database of systematic reviews and implementation reports*, 14(3), 181-234. DOI: <http://doi.org/10.11124/JBISRIR-2016-2477>
- LAINGBUISSON 2018. Care Homes for Older People: UK Market Report. London: LaingBuisson.
- LEGGIERI, M., THAUT, M. H., FORNAZZARI, L., SCHWEIZER, T. A., BARFETT, J., MUNOZ, D. G. & FISCHER, C. E. 2019. Music Intervention Approaches for Alzheimer's Disease: A Review of the Literature. *Front Neurosci*, 13, 132. DOI: <http://doi.org/10.3389/fnins.2019.00132>
- MACANDREW, M., FIELDING, E., KOLANOWSKI, A., O'REILLY, M. & BEATTIE, E. 2017. Observing wandering-related boundary transgression in people with severe dementia. *Ageing & mental health*, 21(11), 1197-1205. DOI: <https://doi.org/10.1080/13607863.2016.1211620>
- MACKENZIE, L., JAMES, I. A., MORSE, R., MUKAETOVA-LADINSKA, E. & REICHEL, F. K. 2006. A pilot study on the use of dolls for people with dementia. *Age and ageing*, 35(4), 441-444. DOI: <https://doi.org/10.1093/ageing/afl007>
- MARCELLA, J. & KELLEY, M. L. 2015. "Death is part of the job" in long-term care homes: Supporting direct care staff with their grief and bereavement. *Sage Open*, 5(1). DOI: <https://doi.org/10.1177/2158244015573912>
- MEILAND, F., INNES, A., MOUNTAIN, G., ROBINSON, L., VAN DER ROEST, H., GARCÍA-CASAL, J. A., GOVE, D., THYRIAN, J. R., EVANS, S. & DRÖES, R.-M. 2017. Technologies to support community-dwelling persons with dementia: a position paper on issues regarding development, usability, effectiveness and cost-effectiveness, deployment, and ethics. *JMIR Rehabilitation and Assistive Technologies*, 4(1), e1. DOI: <http://doi.org/10.2196/rehab.6376>
- MITCHELL, G., MCCORMACK, B. & MCCANCE, T. 2016. Therapeutic use of dolls for people living with dementia: A critical review of the literature. *Dementia*, 15(5), 976-1001. DOI: <https://doi.org/10.1177/1471301214548522>
- MITCHELL, G. & O'DONNELL, H. 2013. The therapeutic use of doll therapy in dementia. *British Journal of Nursing*, 22(6), 329-334. DOI: <https://doi.org/10.12968/bjon.2013.22.6.329>
- MORIARTY, J., MANTHORPE, J. & HARRIS, J. 2018. Recruitment and retention in adult social care services. *King's College London: Social Care Workforce Research Unit*.

- MOYLE, W., JONES, C., MURFIELD, J. & LIU, F. 2020a. 'For me at 90, it's going to be difficult': feasibility of using iPad video-conferencing with older adults in long-term aged care. *Aging & Mental Health*, 24(2), 349-352. DOI: <https://doi.org/10.1080/13607863.2018.1525605>
- MOYLE, W., JONES, C. & SUNG, B. 2020b. Telepresence robots: Encouraging interactive communication between family carers and people with dementia. *Australasian Journal on Ageing*, 39(1), e127-e133. DOI: <https://doi.org/10.1111/ajag.12713>
- MOYLE, W., MURFIELD, J., JONES, C., BEATTIE, E., DRAPER, B. & OWNSWORTH, T. 2019. Can lifelike baby dolls reduce symptoms of anxiety, agitation, or aggression for people with dementia in long-term care? Findings from a pilot randomised controlled trial. *Aging & mental health*, 23(10), 1442-1450. DOI: <https://doi.org/10.1080/13607863.2018.1498447>
- MURPHY, K., LIU, W. W., GOLTZ, D., FIXSEN, E., KIRCHNER, S., HU, J. & WHITE, H. 2018. Implementation of personalized music listening for assisted living residents with dementia. *Geriatric Nursing*, 39(5), 560-565. DOI: <https://doi.org/10.1016/j.gerinurse.2018.04.001>
- NAHCAC. *National Association of Health Care Assistants* [Online]. Available: <https://www.nahcacna.org/> [Accessed 9 June 2020].
- NEUBAUER, N. A., AZAD-KHANEHGAH, P., MIGUEL-CRUZ, A. & LIU, L. 2018. What do we know about strategies to manage dementia-related wandering? A scoping review. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*, 10(1), 615-628. DOI: <https://doi.org/10.1016/j.dadm.2018.08.001>
- NG, Q. X., HO, C. Y. X., KOH, S. S. H., TAN, W. C. & CHAN, H. W. 2017. Doll therapy for dementia sufferers: A systematic review. *Complementary therapies in clinical practice*, 26(1), 42-46. DOI: <https://doi.org/10.1016/j.ctcp.2016.11.007>
- NHS DIGITAL 2018. NHS Workforce Statistics January 2018. London: NHS Digital.
- O'NEIL, M. E., FREEMAN, M., CHRISTENSEN, V., TELERANT, R., ADDLEMAN, A. & KANSAGARA, D. 2011. A systematic evidence review of non-pharmacological interventions for behavioral symptoms of dementia. Department of Veterans Affairs Washington, DC. Available at: <https://www.hsrd.research.va.gov/publications/esp/dementia-nonpharm.pdf>
- OLIVER, D. 2020a. David Oliver: Let's not forget care homes when covid-19 is over. *BMJ*, 369. DOI: <http://doi.org/10.1136/bmj.m1629>
- OLIVER, D. 2020b. Troubled care home market should concern us all. Available at: <https://blogs.bmj.com/bmj/2020/03/04/david-oliver-troubled-care-home-market-should-concern-us-all/>.
- ÖSTERLIND, J., HANSEBO, G., ANDERSSON, J., TERNESTEDT, B.-M. & HELLSTRÖM, I. 2011. A discourse of silence: professional carers reasoning about death and dying in nursing homes. *Ageing & Society*, 31(4), 529-544. DOI: <https://doi.org/10.1017/S0144686X10000905>
- PETROS, S. & JOHN, S. 2019. Ten key messages of the guidelines for family-centered care in intensive care medicine. *Medizinische Klinik, Intensivmedizin und Notfallmedizin*, 114(1), 56-58. DOI: <http://doi.org/10.1007/s00063-018-0481-3>
- PEZZATI, R., MOLTENI, V., BANI, M., SETTANTA, C., DI MAGGIO, M. G., VILLA, I., POLETTI, B. & ARDITO, R. B. 2014. Can Doll therapy preserve or promote attachment in people with cognitive, behavioral, and emotional problems? A pilot study in institutionalized patients with dementia. *Frontiers in psychology*, 5(1), 342. DOI: <https://doi.org/10.3389/fpsyg.2014.00342>
- POLLOCK, A. M., CLEMENTS, L. & HARDING-EDGAR, L. 2020. Covid-19: why we need a national health and social care service. *BMJ*, 369, m1465. DOI: <http://doi.org/10.1136/bmj.m1465>
- PUBLIC HEALTH ENGLAND. 2020a. COVID-19 How to work safely in care homes. Version 2. Revised 27 April 2020. PHE publications gateway number: GW-1237 Available at: <https://www.gov.uk/government/publications/covid-19-how-to-work-safely-in-care-homes>
- PUBLIC HEALTH ENGLAND. 2020b. COVID-19 Putting on and taking off PPE – a guide for care homes. YouTube video. Published 17 Apr 2020. Available at: <https://www.youtube.com/watch?v=ozY50PPmsvE&feature=youtu.be>

- PUBLIC HEALTH ENGLAND. 2020c. COVID-19: infection prevention and control guidance. Updated 27 April 2020 Available at:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/881489/COVID-19_infection_prevention_and_control_guidance_complete.pdf
- PUBLIC HEALTH ENGLAND. 2020d. COVID-19: management of exposed staff and patients in health and social care settings. 15 May 2020. Accessed 18 May 2020. Available at:
<https://www.gov.uk/government/publications/covid-19-management-of-exposed-healthcare-workers-and-patients-in-hospital-settings/covid-19-management-of-exposed-healthcare-workers-and-patients-in-hospital-settings>
- PUBLIC HEALTH ENGLAND. 2020e. Guidance for care of the deceased with suspected or confirmed coronavirus (COVID-19). Updated 20 April 2020 Available at:
<https://www.gov.uk/government/publications/covid-19-guidance-for-care-of-the-deceased/guidance-for-care-of-the-deceased-with-suspected-or-confirmed-coronavirus-covid-19>
- PUBLIC HEALTH ENGLAND. 2020f. Guidance on shielding and protecting people who are clinically extremely vulnerable from COVID-19. Updated 17 April 2020. Available at:
<https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19>
- PUBLIC HEALTH ENGLAND. 2020g. Guidance on social distancing for everyone in the UK. Updated 30 March 2020 Available at: <https://www.gov.uk/government/publications/covid-19-guidance-on-social-distancing-and-for-vulnerable-people/guidance-on-social-distancing-for-everyone-in-the-uk-and-protecting-older-people-and-vulnerable-adults>
- PUBLIC HEALTH ENGLAND. 2020h. How to work safely in care homes: Putting on personal protective equipment (PPE). Informational Poster, Gateway Number: 2020039. Version 1. 23/04/2020 Available at:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/878677/PHE_11606_Putting_on_PPE_062_revised_8_April.pdf
- PUBLIC HEALTH ENGLAND. 2020i. How to work safely in care homes: Taking off personal protective equipment (PPE). Informational Poster, Gateway Number: 2020035. Version 1. 22 April 2020. Available at:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/881005/Taking_off_PPE_Care_Homes.pdf
- PUBLIC HEALTH ENGLAND. 2020j. Recommended PPE for primary, outpatient, community and social care by setting, NHS and independent sector. Gateway number: 2019302. Version 1. 8 April 2020 Available at:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/878750/T2_poster_Recommended_PPE_for_primary_outpatient_community_and_social_care_by_setting.pdf
- RAGLIO, A., BELLANDI, D., BAIARDI, P., GIANOTTI, M., UBEZIO, M. C., ZANACCHI, E., GRANIERI, E., IMBRIANI, M. & STRAMBA-BADIALE, M. 2015. Effect of active music therapy and individualized listening to music on dementia: a multicenter randomized controlled trial. *Journal of the American Geriatrics Society*, 63(8), 1534-1539. DOI:
<https://doi.org/10.1111/jgs.13558>
- RAPAPORT, P., LIVINGSTON, G., HAMILTON, O., TURNER, R., STRINGER, A., ROBERTSON, S. & COOPER, C. 2018. How do care home staff understand, manage and respond to agitation in people with dementia? A qualitative study. *BMJ Open*, 8(6), e022260. DOI:
<http://doi.org/10.1136/bmjopen-2018-022260>
- ROBINSON, L., HUTCHINGS, D., DICKINSON, H., CORNER, L., BEYER, F., FINCH, T., HUGHES, J., VANOLI, A., BALLARD, C. & BOND, J. 2007. Effectiveness and acceptability of non-pharmacological

- interventions to reduce wandering in dementia: a systematic review. *International Journal of Geriatric Psychiatry*, 22(1), 9-22. DOI: <https://doi.org/10.1002/gps.1643>
- ROYAL COLLEGE OF NURSING. 2020. *Membership for HCAs, APs, NAs and TNAs* [Online]. Available: <https://www.rcn.org.uk/membership/nursing-support-worker-join> [Accessed 9 June 2020].
- SCALES, K., BAILEY, S., MIDDLETON, J. & SCHNEIDER, J. 2017. Power, empowerment, and person-centred care: using ethnography to examine the everyday practice of unregistered dementia care staff. *Sociology of health & illness*, 39(2), 227-243. DOI: <https://doi.org/10.1111/1467-9566.12524>
- SCHEEPMANS, K., DIERCKX DE CASTERLÉ, B., PAQUAY, L., VAN GANSBEKE, H. & MILISEN, K. 2020. Reducing physical restraints by older adults in home care: development of an evidence-based guideline. *BMC geriatrics*, 20, 1-14. DOI: <https://doi.org/10.1186/s12877-020-1499-y>
- SCHNEIDER, J. 2017. Paid carers: a new research challenge. *Aging and Mental Health*, 21(7), 758-760. DOI: <https://doi.org/10.1080/13607863.2016.1156049>
- SCHULMAN-GREEN, D. & FEDER, S. Integrating family caregivers into palliative oncology care using the self-and family management approach. *Seminars in oncology nursing*, 2018. Elsevier, 252-263.
- SHIN, J. H. 2015. Doll therapy: An intervention for nursing home residents with dementia. *Journal of Psychosocial Nursing and Mental Health Services*, 53(1), 13-18. DOI: <https://doi.org/10.3928/02793695-20141218-03>
- SKILLS FOR CARE. 2019. *The state of the adult social care sector and workforce in England* [Online]. Leeds: Skills for Care. Available: <https://www.skillsforcare.org.uk/adult-social-care-workforce-data/Workforce-intelligence/publications/national-information/The-state-of-the-adult-social-care-sector-and-workforce-in-England.aspx> [Accessed 25 April 2020].
- SUBRAMANIAN, B., PARSONS, H., FINNER, P. & TOWNSEND, R. 2014. Empathy dolls: are they a source of cross-contamination between patients? *Journal of Hospital Infection*, 87(1), 50-53. DOI: <https://doi.org/10.1016/j.jhin.2014.02.004>
- TELLIE, M. J., LEECH, R. & VAN WYK, N. 2019. Strategies for nurses in antiretroviral clinics to mitigate symptoms of compassion fatigue. *Africa Journal of Nursing and Midwifery*, 21(1), 1-18. DOI: <http://doi.org/10.25159/2520-5293/4907>
- THE NATIONAL CARE FORUM. 2020. *#ringofsteel around care homes* [Online]. Available: <https://www.nationalcareforum.org.uk/blog/ringofsteel-around-care-homes/> [Accessed 25 April 2020].
- TRAVERS, C., BROOKS, D., HINES, S., O'REILLY, M., MCMASTER, M., HE, W., MACANDREW, M., FIELDING, E., KARLSSON, L. & BEATTIE, E. 2016. Effectiveness of meaningful occupation interventions for people living with dementia in residential aged care: a systematic review. *JBI database of systematic reviews and implementation reports*, 14(12), 163-225. DOI: <http://doi.org/10.11124/JBISRIR-2016-003230>
- TSOI, K. K. F., CHAN, J. Y. C., NG, Y. M., LEE, M. M. Y., KWOK, T. C. Y. & WONG, S. Y. S. 2018. Receptive Music Therapy Is More Effective than Interactive Music Therapy to Relieve Behavioral and Psychological Symptoms of Dementia: A Systematic Review and Meta-Analysis. *J Am Med Dir Assoc*, 19(7), 568-576.e3. DOI: <http://doi.org/10.1016/j.jamda.2017.12.009>
- TSUI, E. K., FRANZOSA, E., CRIBBS, K. A. & BARON, S. 2019. Home care workers' experiences of client death and disenfranchised grief. *Qualitative health research*, 29(3), 382-392. DOI: <https://doi.org/10.1177/1049732318800461>
- VIS, J.-A., RAMSBOTTOM, K., MARCELLA, J., MCANULTY, J., KELLEY, M. L., KORTES-MILLER, K. & JONES-BONFIGLIO, K. 2016. Developing and implementing peer-led intervention to support staff in long-term care homes manage grief. *Sage Open*, 6(3), 2158244016665888. DOI: <https://doi.org/10.1177/2158244016665888>
- VOLKERT, D., BECK, A. M., CEDERHOLM, T., CRUZ-JENTOFT, A., GOISSER, S., HOOPER, L., KIESSWETTER, E., MAGGIO, M., RAYNAUD-SIMON, A. & SIEBER, C. C. 2019. ESPEN guideline

on clinical nutrition and hydration in geriatrics. *Clinical nutrition*, 38(1), 10-47. DOI: <https://doi.org/10.1016/j.clnu.2018.05.024>

WITTENBERG, E., BULLER, H., FERRELL, B., KOCZYWAS, M. & BORNEMAN, T. 2017. Understanding family caregiver communication to provide family-centered cancer care. *Seminars in oncology nursing*, 33(5), 507-516. DOI: <https://doi.org/10.1016/j.soncn.2017.09.001>

WITTENBERG, R., HU, B., JAGGER, C., KINGSTON, A., KNAPP, M., COMAS-HERRERA, A., KING, D., REHILL, A. & BANERJEE, S. 2019. Projections of care for older people with dementia in England: 2015 to 2040. *Age and Ageing*, 49(2), 264-269. DOI: 10.1093/ageing/afz154

Table 1: rapid, evidence-based expert reviews (anonymised for review)

ER	Review title	Authors	Methods	Evidence reviewed	Gaps in evidence identified
1	End of life care when unsure what is best.	Claire Goodman	Expert review of literature reviews that CG authored and co-authored on end of life care for people living and dying with dementia and Google Scholar forward citations of framework paper on uncertainty.	Four reviews and seven peer review papers	Intervention studies using co-design approaches to achieve a level of “practical certainty” for the minority of residents whose dying trajectory is uncertain.
2	Hydration and COVID-19	Diane Bunn Angela Dickinson	Searches of Medline and CINAHL 2015-2020 (to identify and update evidence reviewed by the authors in three previous systematic reviews published in 2015/2016). Combining index terms: aged and homes for the aged and dehydration or fluid intake. Hand searches of reference lists. Evidence summarised.	17 peer-reviewed papers reporting evidence of effective care to support fluid intake and prevent dehydration in older care home residents.	Need for further robust studies exploring management of oral hydration and prevention of dehydration in older people particularly in care home settings.
3	Supporting families at a distance	Andrea Mayrhofer	Search of PUBMED combining index terms in titles or abstracts: care homes OR nursing homes; AND information OR communication AND family OR carer. Filtered by ‘reviews, last 5 years’.	Scanned 781 abstracts; of these: downloaded 27, of these: selected 7 papers to feed into the top tips.	Lack of studies about ‘ <i>staff extending care beyond the care home</i> ’ or ‘ <i>staff supporting families at a distance</i> ’. Had to draw on relevant literature in intensive care units, hospices and palliative care for transferable learning.

Producing Top Tips for care home staff during COVID19

4	Using video-calls to help residents and families stay in contact.	Anne Killeth and Ann-Marie Towers	Rapid review of evidence supporting care home residents with dementia to use tablets, smartphones and video-enabled devices to communicate with their families. Searched PUBMED and CINAHL (10 April 2020) and hand-searched reference lists. Used terms dementia (title), communication (title/abstract), technology or digital or virtual or on-line or remote or tablet or phone (title/abstract). Results – PUBMED 72 abstracts scanned, CINAHL 102 abstracts scanned.	42 peer reviewed research articles 2002-2020 selected for review. Of these 15 fed into the top tips.	Very little on care home residents with dementia using tablets or screens for video calls/social interaction. Few practical strategies to support successful interaction on video enabled devices.
5	Supporting residents who do not understand self-isolation and social distancing,	Melanie Handley and Tamara Backhouse	Review of evidence for supporting people with dementia who walk with purpose and the use of restraint in care homes and hospitals. Searched PUBMED and lateral searches.	19 peer reviewed articles 2010 – 2020 fed in to the top tips.	Limited number of practical strategies, most relied on one-to-one support. When restraint would be ethically acceptable. Which restraint type/s would be least restrictive.
6	Using dolls to comfort people with dementia	Elspeth Mathie and Frances Bunn	Review of evidence on providing comfort to people in care homes, as an alternative to physical contact. Original search doll/pet/toy therapy Searched PUBMED, hand-searched reference lists and key word searches in Google Scholar.	14 papers from PubMed search and 8 papers from hand searched reference lists (3 pre 2010) identified. 9 of these fed into the top tips.	More research evidence needed; more robust studies, longitudinal, randomised control trials on doll therapy within care home settings.

Producing Top Tips for care home staff during COVID19

7	Using music to provide comfort and reassurance.	Frances Bunn	Drew on realist review on multisensory interventions for people with dementia living in care homes (Bunn et al 2018). Conducted updated PubMed and Google Scholar search for papers on the use of music in care homes.	18 primary studies and 6 reviews on music therapy (from Bunn 2018). Plus 8 papers from updated search.	More evidence needed on care home led interventions. Limited evidence on impact of music listening.
8	Supporting staff following multiple deaths in care homes.	Kathryn Almack	Rapid review of evidence of specifically supporting and addressing care home staff following deaths of residents. Conducted PubMed and Google Scholar search for papers using the terms (Care home staff) AND bereavement OR grief 2000-2020 Hand-searched reference lists and citations of previously published articles	PubMed – results: 15 papers. 5/15 of relevance to the topic of interest. Google Scholar and hand-searched reference lists/ citations of previously published articles – found a further 7 relevant papers. Two additional references from nursing and hospice literature were also included.	Top Tips drew on transferrable learning from nursing or hospice literature and research about how staff deal with large disasters and previous pandemics. More research needed to explore and test bereavement support interventions in care homes. Lack of evidence around impact of multiple deaths on care home staff.