Mersey Care
NHS Foundation Trust
Community and Mental Health Services

Mental Health Support to Care Homes during the COVID-19 Pandemic

Resources

July 2020

Complex Care Psychology Service

Contents

1. Introduction

These resources are designed to help you support care home residents with psychological issues that may either arise, or be exacerbated by the current COVID-19 pandemic and the related public health restrictions.

The complex care psychology team is available to offer advice, support and consultation around issues such as:

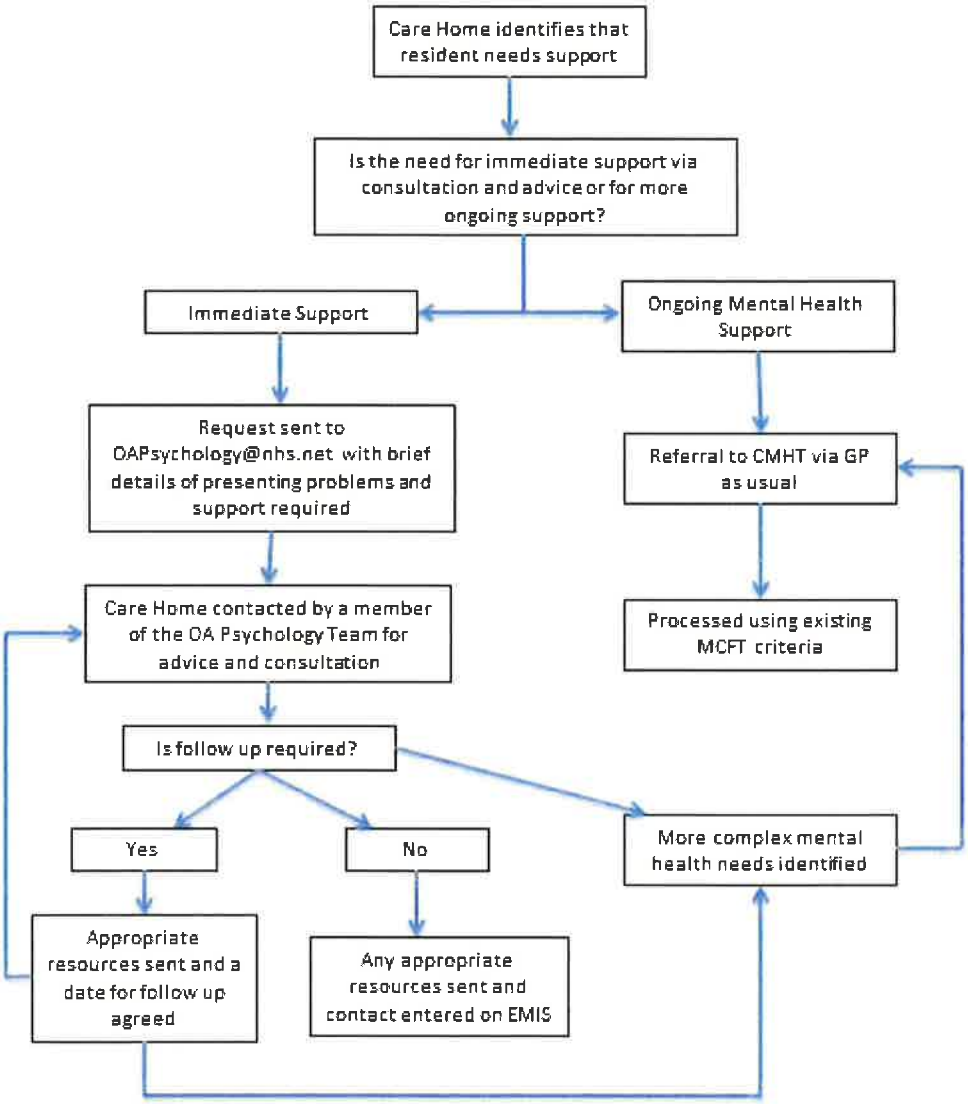
- Support with resident behavioural issues.
- Activities to improve psychological well being including activities to distract residents and to stimulate both physical and mental abilities.
- Anxiety reduction techniques.
- Family carer and relative advice and support with supporting residents at this time, including supporting carers with end of life issues.
- Sign posting information and updates.
- Work as part of the Integrated Care Team supporting care homes.
- Staff support via reflective practice.

The team can be contacted by emailing: OAPsychology@nhs.net from the care home's own nhs.net address.

Further resources to support specific issues are available on request.

2. Referral Pathways

If support is required for a resident:



3. Online and phone psychological support from Mersey Care

Online and phone psychological support from Mersey Care

Mersey Care
NHS Foundation Trust
Community and Mental Health Services

	Who can access?	When and how is it accessed?	What is provided?
Urgent mental health support 0800 145 6570 (Freephone)	Anyone 16+ self-referral or any professional	24/7 by freephone	• 24/7 access to mental health support (including people in crisis) • 24/7 contact line for emergency services that will divert mental health activity away from A&E • 24/7 contact line for primary care for urgent/emergency referrals for mental health assessments.
Psychological support line 0151 473 0303 ask for the psychological support team	Anyone 16+ self-referral	8.00am to 8.00pm phone Monday to Sunday	• Low level psychological support to those impacted by the COVID-19 situation, such as those experiencing anxiety or depression • This is not an immediate access telephone therapy service, but rather a listening ear support line – allowing space to discuss psychological needs, which may result in signposting to resources, information or other services and agencies.
Talk Liverpool 0151 228 2300 talkliverpool.nhs.uk	Anyone 16+ self-referral or GP	9.00am to 6.00pm by phone Monday to Friday 24/7 online via talkliverpool.nhs.uk	**Treatment for people with the following common mental health problems:** Depression, generalised anxiety disorder, social anxiety disorder, panic disorder, agoraphobia, obsessive-compulsive disorder (OCD), specific phobias (such as heights or small animals), PTSD, health anxiety (hypochondriasis), body dysmorphic disorder, mixed depression and anxiety (the term for sub-syndromal depression and anxiety, rather than both depression and anxiety). Evening appointments can be made available if required.
The LIFE ROOMS 0151 478 6556 liferooms.org	Anyone 18+ self referral or any professional	9.00am to 5.00pm phone Monday to Friday 24/7 online learning/activity resources	• Online staying well at home learning courses • Pathway advisors who can support and advise with debt management, employment, housing issues, benefits and more • Social inclusion advice for isolated community groups.
NHS Mersey Care NHS Foundation Trust Staff support counselling service 0151 330 8103	Mersey Care staff only self-referral	9.00am to 8.00pm by phone Monday to Friday by phone evenings and weekends	• Counselling, cognitive behavioural therapy (CBT) and other evidence based psychological interventions for depression, generalised anxiety disorder, social anxiety disorder, panic disorder, agoraphobia, OCD, specific phobias (such as heights or small animals, PTSD and health anxiety (hypochondria) • Access to telephone support for Mersey Care staff in distress (not crisis support).

4. Supporting older People living with dementia during self-isolation

the british
psychological society
promoting excellence in psychology

Division of
Clinical Psychology
Faculty of the Psychology
of Older People

GUIDANCE

Supporting older people and people living with dementia during self-isolation

A COMPASSIONATE RESPONSE TO COVID-19

Covid-19 and finding the strength to cope: We keep being told that these are unprecedented times and it is true that as humans we have never encountered this new Corona virus (Covid-19). However, as individuals we have encountered adversities before and as a species we have evolved to be able to deal with all sorts of threats. So we have within us the skills that we need to get through. But what can be tricky is that when we are faced with overwhelming threat, we have natural responses such as fear, anger or feeling too overwhelmed to do anything. These responses can be really helpful in dealing with short term problems, but if we live with those kinds of feelings ruling the show for long, they have damaging effects on our mental health and even our immunity.

SO WHAT CAN WE DO INSTEAD?

Compassion focused therapy brings our attention to the strength we gain when we focus on the fact that ‘we’re all in the same boat’. And now really is a time in our lives, like no previous time, when we realise that across the globe we are sharing in this challenging period.

To come through this well, we need to have the courage to turn our attention to the challenges and difficulties we are facing… and then do something about them. And there are small things that we can do.

As well as the bad news, there are suddenly good news stories on the radio and television: People sharing their ideas about how we can be flexible, how we can hold in mind people that normally are not thought about, how we can pool our resources and skills and work together as communities.

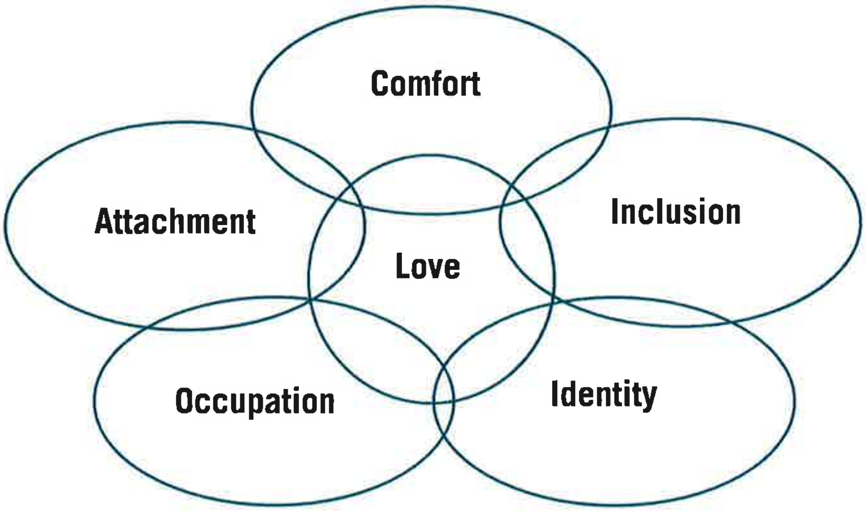
We are having to tolerate that we may not be able have everything that we want, but we may be able to survive with what we need… especially if we adopt a sharing *lagom* philosophy. What really matters is coming into clearer focus.

And after many years of being used to helping others, we may be starting to realise that we need to open our hearts to receiving offers of help and kindness. Feeling gratitude for all the ways that people have already changed their lives for the greater good, like the children putting their schooling on hold to try to protect their elders.

There is no certainty about what tomorrow will bring but today we can start to give more air to our inner light, kindle our inner fire of courage to face this challenge with kindness for ourselves, empathy for others and a graceful calmness for the world around us.

MEETING THE PSYCHOLOGICAL NEEDS OF PEOPLE LIVING WITH DEMENTIA DURING SOCIAL-ISOLATION

Tom Kitwood (1997) defined the psychological needs of people living with dementia as; love, comfort, attachment, occupation, inclusion and identity. These are commonly displayed as the 'Kitwood Flower'.



In times of challenge, such as those we are currently facing, it is even more important that we think about the most effective ways to help people living with dementia to meet their psychological needs and promote wellbeing.

LOVE

Everybody needs love and acceptance. We can probably all think of times when we feel love whether this is loving a person, enjoying an activity, having a favourite meal or self-love. Having to self-isolate may make it harder for us to do the things that make us feel love or loved, as we can't see the people we usually see or access activities we usually engage in. You could think about making a photo album with pictures of all the people you care about so you can look at them whenever you want to. How about adding in stories of times you have enjoyed together? Make sure you look after yourself and maybe spoil yourself a bit; get your favourite food in; listen to your favourite music; sit in the garden and enjoy nature or watch a film you really enjoy.

COMFORT

We all need our basic needs met including our emotional need to not feel anxious. It is natural that with all the news about the Covid-19 virus and feelings of uncertainty we might feel more anxious than usual. There are lots of ways we can control our anxiety. It might be useful to limit the amount of time we spend watching the news – there are lots of confusing messages out there that can increase anxiety. Some people find that practicing mindfulness, or trying relaxation techniques help with anxiety. A lot of people now enjoy mindfulness colouring to give them something to focus on rather than thinking of what is going on in the world that we can't control!

ATTACHMENT

Attachment describes the connections we have in life. These attachments, or connections, are important in helping us feel safe and secure. Being in self-isolation is likely to mean we can't physically spend time with the people who make us feel safe. It might feel hard to be separated from these people but there are still ways to stay in touch. The telephone is a great way to stay in contact with people. It might be helpful to keep a list of telephone numbers for friends and family by the phones so you can find them easily. If you use a tablet, computer or smart phone you might consider video messaging. If you have never done this before there are some excellent guides produced specifically for people living with dementia. When people aren't around consider other things that make us feel secure like a pet or a favourite piece of clothing.

OCCUPATION

It is vital for our wellbeing that whilst we are self-isolating we still find meaningful and enjoyable thing to do. This might feel challenging at first but look around you and think of all the opportunities that are available to you. Routine and structure in your day are likely to help in maintaining activity during this time. If you have a garden try to get some fresh air each day. This is a great time to do all the tidying and sorting in the house that you have always meant to do. Dig out those jigsaw puzzles from the back of the cupboard or maybe listen to a play on the radio or an audiobook. It will be important to keep ourselves fit and well and so think about doing some exercise every day as well.

INCLUSION

Many people living with dementia get a lot of support from linking up with other people in a similar situation. It helps our wellbeing to feel that we are a part of something. At the current time many social groups will have stopped but maybe you could find other ways to stay connected. Think about writing a letter to a friend of family member. Some services are still offering groups by videoconferencing so you might be able to join one of these. The dementia engagement and empowerment project run the dementia diaries scheme where people living with dementia leave stories about their experiences. It might help to hear how others are doing at this time.

IDENTITY

A sense of identity helps us define and remember who we are as a person. The way other people treat us reinforces our beliefs about ourselves. During the time we are isolated it will be important to remind ourselves of all the things that are important to us. That might be by having things that are important to us, around us, such as a picture or photograph we like or playing music we have enjoyed. Playlist for life offer advice on putting together a list of your favourite music. Some people make a life story book where they put all the things that are important to them in one place.

Whatever happens do not be afraid to ask for help. There is lots of support out there.
You could contact your local services or the following organisations might be able to help:

Alzheimer's Society – 0333 150 3456 (or if you speak Welsh – 03300 947 400)

Age UK – 0800 678 1602

The Silver Line – 0800 470 80 90

HOW CAN WE HELP PEOPLE WITH MEMORY PROBLEMS AND LIVING WITH A DEMENTIA TO UNDERSTAND, REMEMBER AND FOLLOW THE COVID-19 ADVICE?

Use posters and reminders in the house. Pictures and words are best. Put them on the doors, next to the sink and in places that are regularly passed. Point out the poster and make a clear statement 'We need to wash our hands'.

Keep communication as clear as possible and try to focus on what you need to do rather than why you must do it.

Tell your loved one that this is advice from a person they trust – maybe the GP, their children, the government so they understand this isn't your choice.

Use your digital devices to set reminders – 'It's time to wash your hands'
'It's time to phone a friend'.

Link washing hands with a song, music or story. Pay close attention to details such as how the water feels, the smell of the soap and memories linked to times when you wash hands (work, school, hospitals).

People with dementia, at all stages of difficulty, will pick up on anxiety and panic.
Try to stay calm, matter of fact and upbeat.

Limit access to the news, radio and conversations about covid-19 and the risks. This heightens anxiety and is hard to explain.

Prioritise getting on well if you can, behaviours are easier to change if you keep the mood light and encourage.

Encourage family and friends to maintain regular phone and digital contact and ask them to explain that they are washing hands, keeping their distance and staying at home. We are all doing this together.

Keep busy in the house as much as possible and if you need a break to go out, use the garden or make a plan to sit and look out of the window. If you feel you really need to be outside, plan your walk carefully to maintain social distance. You can take a trip in a car.

Use your local community well. Explain to neighbours that your loved one may not remember the guidance and that they need to contact you if they are talking a walk outside. Remind everyone that this is not breaking rules it's simply not remembering.

If you can it might be an idea to identify two 'flu friends' who you can call on for extra help?

It is possible that your loved one will become suspicious about the advice and the isolation. Reassure them that they are safe at home and keep in mind a list of activities, songs, conversations and interests that you can use quickly to maintain their wellbeing.

Those with dementia can easily develop a delirium. Pay close attention to changes in levels of confusion or unusual behaviour. Seek medical advice if you think they are showing symptoms – NHS 111 or phone the GP/CPN.

Use the Herbert Protocol with your local police force. This lets them know all about your loved one and allows for quick action if they go missing. Find more information by calling your local Police station or calling Age UK.

Having a plan in place can help ease your worries if you are not able to care for those you look after at any point in the future. See Carers UK for practical advice on planning for emergencies.

The National Activity Providers Association are currently providing free access to their website for ideas and activities in the home.

Dementia UK also has good advice.

If you are someone living with dementia you may want to connect digitally through the Dementia Engagement Empowerment Project. You may want to become a dementia diarists or to listen to what others people with a dementia are doing, learning and sharing.

Connect with others virtually maybe through dementia diaries.

1. **Focus on what you can control;**
2. **It's helpful to develop routines;**
3. **Look after yourself – 'you cannot pour from an empty cup';**
4. **Find a way to be 'out' when you are in (contact friends and family – connect with other groups).**

Please do ask for help. Contact your local Alzheimer's Society
or Age UK for a conversation.

Link with friends and **look after yourself.**

GUIDANCE FOR OLDER PEOPLE DURING SELF-ISOLATION

The government has responded to concerns over the spread of coronavirus by asking us all to strictly observe social distancing measures to limit the transmission of the virus. Those aged 70 or older are considered more vulnerable to severe illness from coronavirus and are asked to be particularly stringent in their application of these measures. Additionally, people with an underlying health condition have been asked to self-isolate for 12 weeks.

Self-isolation due to social distancing measures can result in increased distress due to e.g. lack of company, confined space, worries about infection, worries about money and strained family relationships. Confusion, anger, depression and anxiety are common responses in those who have had to endure quarantine for a number of weeks or months.

The effects of self-isolation can be worsened by longer duration, frustration, boredom, stigma, and inadequate supplies or information.

As an older adult, you may already live alone and/or rely on others for support. Self-isolation may make it more difficult for you get the support you need and may make you feel anxious or low. The suddenness of these changes in your life and to the roles you hold dear leaves little time to adjust.

The ideas that follow are provided to help you live as well as possible during self-isolation. They are consistent with current NHS guidance about how to improve mental wellbeing ('five ways to wellbeing') and share features of our guidance for those living with dementia.

CONNECT

Being 'connected' is linked to better wellbeing because it gives us a sense of belonging and self-worth, and is a source of emotional support.

Connecting with others in the same physical space is difficult during self-isolation. You may have supported your family up to now by looking after grandchildren and find that you can no longer do this. You may feel that your self-isolation is causing your family additional worry. You might be wondering what all the fuss is about and have had some disagreements with your loved ones about this.

Technology provides us with some solutions but it is not a substitute for actual contact. You may also take time to connect more with yourself, nature, nations, pets and/or spiritual needs:

- Switch off television: This helps limit your exposure to news, which may be making you feel anxious, and allows you to focus on the loved ones in your home.

Or

- Switch on the television! Watching a favoured television programme and reading a good novel have been found to reduce feelings of loneliness;
- Maintain social contacts over the telephone;
- Video conference: FaceTime, Skype and Zoom are platforms for seeing and speaking to loved ones at the same time. Although telephone is great, seeing facial expressions can help people feel less lonely. You may need some help from a loved one to put this in place. Additionally, help with this sort of technology can be found at Fountain Digital;
- 'Create warmth'! The same parts of the brain are activated by heat, and by warmth from interpersonal contact. Creating opportunities for heat e.g. a hot drink and warm bath can mimic the effects of touch and increase our sense of connectedness;
- Spend time in nature;
- Revisit old photos/family films and share memories: Nostalgia has been found to enhance feelings of security and reduce loneliness;
- Email a different friend each day and make time to respond;
- Write a card or letter to a friend and ask a neighbour to post it for you;
- Discuss your worries with a friend or with your therapist/psychologist;
- Some more helpful ideas can be found at the Campaign to End Loneliness.

BE ACTIVE

You may find during self-isolation that your confidence to try new things is reduced. You might believe that the way you feel is inevitable given your age and that there is very little you can do to change this. You may hold the view that you are powerless in the face of self-isolation and find that it impacts on every part of your day to day life as a result.

However, making conscious choices about our behaviour can boost our mood. As little as 10 minutes of exercise a day can make us feel better, both physically and emotionally. And activity that stimulates our brain can help us feel more alert. You may want to try the following during self-isolation:

- Exercise: There are lots of free exercise programmes/sessions available on the internet or on apps on your smartphone. You may want to ask for assistance to access these. You could try yoga, tai chi or other martial art practice, or increase your movements from your armchair. Other activities with mood-boosting effects include housework, gardening, using the stairs if it's safe to do so, dancing round the house and safely going for a walk.
- There are lots of ways you can stimulate your mind during self-isolation. Jigsaws, puzzle books or games, reading, colouring books for adults, painting or drawing, singing along to your favourite song, playing a musical instrument, sorting out your finances, cooking or baking and craft activities.

NOTICE

We tend to spend a lot of time dwelling on the past or worrying about the future. This can be tiring, and not very helpful. Instead, 'savouring the moment', often referred to as 'mindfulness', has been found to enhance wellbeing:

- Breathing or meditation exercises: You can find lots of free exercises on the internet or through apps on your smart phone e.g. apps like Calm and Headspace. Ask someone if they can provide you with some if you have difficulties accessing the internet.
- Self-care is important during self-isolation and provides a great opportunity for mindfulness: Shower or bath frequently and take time to notice the sounds, smells and sensation of the water on your skin; do hair and nails; use hand cream or body lotion to maintain suppleness and notice how it feels.
- Mindful eating: Lay the table or tray for your meal and focus on the sight, smell and taste of your food.
- Reflect using music, prayer, the outdoors, silence; take a few moments to be thankful, notice and appreciate beautiful things around you.

LEARN

Learning new skills can help lift your mood, boost your self-esteem and give a sense of purpose. Setting yourself goals can help you see even greater benefits. It is also helpful to have good information about the reason for your social isolation:

- Get advice from NHS and read public health guidance to gain facts and dispel fear;
- Research online something that you have always wanted to know more about;
- Learn new words/look up definitions in the dictionary;

- Create a book club with friends/loved ones and discuss books over the phone or video conferencing;
- Challenge yourself to complete new puzzles, crosswords etc.;
- Learn to play a musical instrument;
- Learn a new language.

GIVE

Giving has been linked with a sense of reward, purpose and self-worth. Those who give to others are more likely to rate themselves as happy. You might feel it is hard to give to others during self-isolation. However even giving a smile, encouragement, your time, a wish/prayer, thanks, and other 'random acts of kindness' has the power to boost your mood.

These 'five ways' help us build on our strengths and increase our resilience. By promoting our self-esteem, sense of being valued, and a positive attitude, they can help us 'bounce back' from challenges we encounter. There are already many examples of compassion in our communities during this crisis. Leaflet drops with offers of help, businesses changing their procedures to meet the needs of the isolated, online communities sharing information to support home schooling, medical students setting up relief initiatives to provide child care/grocery drops for NHS staff, websites and apps making their content free for the duration of the crisis, churches taking a central role in supporting communities, milkmen delivering groceries to the housebound… to name but a few. As we all experience restrictions on our movement, freedom and choice. We have an opportunity to emerge from this crisis with fewer divides and greater empathy.

the british
psychological society
promoting excellence in psychology

St Andrews House,
48 Princess Road East,
Leicester LE1 7DR, UK

☎ 0116 254 9568 www.bps.org.uk info@bps.org.uk

Incorporated by Royal Charter Registered Charity No 229642 : BRE26I/08.04.2020

5. Death and grieving in a care home during Covid-19: The experience of care staff, residents and families

the british
psychological society
promoting excellence in psychology

GUIDANCE

Death and grieving in a care home during Covid-19: The experience of care staff, residents and families

This document was prepared by Dr Frances Duffy, Consultant Clinical Psychologist, Northern Health and Social Care Trust in conjunction with Dr Becci Dow, Consultant Clinical Psychologist, Oxford Health NHS Foundation Trust and Dr Polly Kaiser, Consultant Clinical Psychologist, Pennine Care Foundation Trust. On behalf of the BPS Covid-19 Bereavement and Care of Relatives Group (Chair – Prof Nichola Rooney).

Many people enter a care home because they are no longer able to live independently in their own home. For these people, the care home is their home.

> *'There is growing international evidence that people living in care homes are particularly vulnerable to severe COVID-19 infections and that they are experiencing high rates of mortality as a result'*[1].

In these unprecedented times, there are understandable additional pressures, fears and challenges for residents, care staff and their family and friends.

This document should be read with *Supporting yourself and others: coping with death and grief during the Covid-19 pandemic*[2] which is a guide to help people to understand their experience of grief during this strange and challenging time. The document explains some of the emotions which people may experience and also offers some advice on what might be helpful.

The circle of people who look after and support care home residents are presented with a unique set of circumstances. Care staff will have similar experiences of grief but they will also have experiences that are different. This means that the support they need may be different.

THE EXPERIENCE OF CARE STAFF

Residents in care homes are generally older and more frail and, because of this, death of a resident is something that is expected in a care home. This means that death is something that care staff regularly have to cope with. While care staff have considerable experience of death, it does not make each death any easier to cope with.

Care staff develop close relationships with the residents that they care for. The resident can feel like part of their family. The experience of loss and grief can be the same as when any member of the family dies. What is not normal in the Covid-19 pandemic is the number of residents that are dying in a short time. While care staff may have developed ways of coping with the death of one resident, they may find it much more difficult to cope with the death of multiple residents in close proximity.

Part of the role in supporting a resident at the end of their life is to offer comfort, relieve symptoms and preserve dignity. Care staff may be concerned that they were unable to care for the residents in the way that they would have liked to because of the restrictions on contact and the need to wear Personal Protective Equipment (PPE). How a resident dies in a care home now, during the time of Covid-19, may be different than what would normally happen. Family and friends are not permitted to visit. All of the support and care is offered by care staff. Care staff need to support the resident but also offer comfort and reassurance to their loved ones who are naturally distressed because they were unable to be there.

Care staff may be more frightened when offering care, regardless of whether the resident has tested positive for Covid-19 or not. Thinking about this fear and the need to change the way care is offered may cause feelings of guilt. This misplaced guilt can have a negative impact and add to the experience of grief. It is important to understand that fear is normal and it is essential that the way care is offered changes in order to protect care staff, the resident and others.

What can help care staff is to focus on all of the care. They should remember what they are pleased with, what they are good at and did well. Staff should be reminded that there might be times it is not exactly perfect, but this happens in the complex care work they provide.

The experience of grief is happening at the same time as care staff worry about their own health and the health of their family at home.

Normal ways of coping with the death of a resident before restricted visiting and physical distance may no longer be available. Covid-19 can evoke a range of feelings such as of powerlessness and despair. Staff shortages as colleagues become ill and the availability of PPE are an additional cause of pressure, stress and anxiety which impacts on grief. Everyone is experiencing the stress and the experience of loss but we all manage this experience differently. Some people will cry, others may be angry and others may use humour. Care staff will rely on their colleagues more than ever but at times, may also become angry or irritated by them during these circumstances.

The whole care team is very important to the residents at this vulnerable time in their lives. Remembering together all of the efforts everyone has made, all of the thought and care the team has given, is an important way of reflecting the essential role they provide. There are many suggestions of what might help in the *Supporting yourself and others: coping with death and grief during the Covid-19 pandemic* document.

Note to Care Staff – Be kind to yourself and make sure you find things to do to help you to cope with how you feel. Managing your own grief and that of residents and their families is a huge burden.

THE EXPERIENCE OF STAFF WHO DID NOT KNOW THE RESIDENTS WELL?

Even if care staff don't know someone well, their role at this stage of the residents lives has value and makes a difference. Even with all of the changes that Covid-19 brings, being present, talking, caring and thinking how best to help someone will have made a difference.

Working in many settings at this stage and possibly hearing about many deaths can feel overwhelming. A staff member may not know the rest of the care team that well, for various reasons, but they should be encouraged to reach out. Sharing feelings, fears and distress can help connect people who are in a similar position.

Care staff should look out for resources at the start of a shift. Who is there to help with the practical tasks? Who will guide you through the process and who can you speak with if your resident has died?

THE EXPERIENCE OF RESIDENTS LIVING IN A CARE HOME DURING COVID-19

Residents have a range of strengths and weakness and so how they respond will be different. Some may be aware of the seriousness of the situation through the news, care staff and what they can see happening around them. Others may be aware that something serious is happening but not fully understand what it is. Even residents in the moderate to later stages of dementia will be affected by the changes in the day to day life of the care home. They may experience a range of emotions, sadness, anxiety, low mood, anger, frustration or numbness. This means that they will need more emotional support at a time when staff have less time and may be less available to listen because of their own worries.

Residents will notice that care staff are wearing PPE, busier, anxious or not at work. New staff that they don't know may not support them in the same way as the regular staff. All of this will increase their anxiety. When we are worried we turn to the people we love and trust for comfort and support. Residents are unable to see loved ones face-to-face because of restricted visiting and may not fully understand why they do not visit and may also be worried about them. If they don't have someone to share their worries with they may become more worried and feel very lonely.

There are also likely to be changes to normal routine. Residents may not be spending time in the lounge or the dining room with the people they normally would. They are being asked to keep a physical distance from people they normally sit close beside. This can feel very unsettling and they may not fully understand why this is happening.

Some residents may not be able to come out of their rooms because they are unwell or have tested positive for the virus and others will have died. They will be missed by some of the other residents who will ask where they are. Some residents may become more distressed as they worry about what is going to happen to them or because they don't understand what is happening.

THE EXPERIENCE OF FAMILY AND FRIENDS

Family and friends may experience a range of different feelings following the death of a loved one living in a care home. Many of these will be similar to the experiences detailed in *Supporting yourself and others: coping with death and grief during the Covid-19 pandemic* but others will be different.

In the same way that families of people who have died in hospital feel, they may be worried about how their loved one died. The difference is that the person died in familiar surroundings with the staff they knew well. This should give family some comfort during this very difficult time.

Some people may feel relief that the person has died, particularly if they have been frail for some time or they were at the end stages of dementia. They may then experience guilt as a consequence of this relief.

With dementia, the person and those who love and care for them experience a series of losses as the condition progresses. Some people may have grieved for the person some time ago as the person lost ability and dementia changed their relationship.

Note to family and friends – It is important to know that all of these feelings are normal. There is no right or wrong way to grieve. Be kind to yourself and talk to family and friends about how you are feeling.

Follow the advice in *Supporting yourself and others: coping with death and grief during the Covid-19 pandemic.*

HOW CAN STAFF SUPPORT RESIDENTS?

Try to maintain communication with residents, even if it feels like it's always sad news. As we know, older people are a wise and resilient group. Even if care staff feel that residents will become more distressed, they should talk to them, as they are already aware that something is happening.

For residents who have additional needs with memory and understanding the guidance *Supporting older people and people living with dementia during self-isolation*[3] and *Supporting Carers and Care Staff to Understand and Respond to Changes in Behaviour in People with Dementia During the COVID-19 Pandemic*[4] will help. Information may need to be repeated many times if residents forget and ask questions again. For some residents you may feel it is better to focus on their personal wellbeing and distraction, using a gentle statement such as 'yes there are sad things happening but we're here to help you'.

The usual focus on activity and wellbeing is really important. Routines and being connected to other people are important ways to feel safe. Try to support residents to maintain contact with family and friends by phone or video calls. Are there school children or local people who could send messages?

Remember that residents may feel apprehensive with staff wearing PPE so explain to the residents that is is to protect them from the virus. Create a laminated card with your name and picture on it to help them to understand who you are.

WHAT CAN MANAGERS DO TO SUPPORT CARE STAFF?

Managers and supervisors may not know what to say or may worry about saying the wrong thing. This situation is not like anything any of us has experienced before.

Staff may be feeling powerless, overwhelmed and feel that there is nothing they can do. It is important to remind them how important their care has been and how much they are valued.

Managers will be very busy at this time with numerous demands on their time. It is essential, however, that staff feel that they can speak to and seek support from senior colleagues.

Where possible, develop rotas to accommodate regular and more frequent breaks. This may be difficult in a climate of reduced staff and creativity may be required. Time out is essential for staff at a time when their work can be emotionally draining.

At the end of a shift offer a check-in with staff to ask how they are feeling. It can be helpful for staff to come together at their end of a shift to recognise how difficult the shift has been and to offload feelings before they go home. This can be a challenge with staff shortages but it doesn't have to be a long session, even 10 minutes would be enough. Some people may not want to do this but for others it can be helpful. Check-ins should be facilitated, if possible, by a senior member of the team who can offer support.

Consider ways that the staff can collectively remember the residents who have died and celebrate the person's life.

Services such as CRUSE or local wellbeing helplines can offer support and advice.

SUPPORT SERVICES

CRUSE bereavement care has a range of resources and a 24-hour helpline.

https://www.cruse.org.uk 0808 808 1677

REFERENCES

[1] Adelina Comas-Herrera (CPEC, LSE) and Joseba Zalakain (SIIS) 12 April, 2020 Mortality associated with COVID-19 outbreaks in care homes: early international evidence. https://ltccd.org/2020/04/12/mortality-associated-with-covid-19-outbreaks-in-care-homes-early-international-evidence/

[2] The British Psychological Society (2020). *Supporting yourself and others: coping with death and grief during the Covid-19 pandemic.* https://www.bps.org.uk/sites/www.bps.org.uk/files/Policy/Policy%20-%20Files/Supporting%20yourself%20and%20others.pdf

[3] The British Psychological Society (2020). *Supporting older people and people living with dementia during self-isolation.* https://www.bps.org.uk/sites/www.bps.org.uk/files/Member%20Networks/Faculties/Older%20People/Supporting%20older%20people%20and%20people%20living%20with%20dementia%20during%20self-isolation.pdf

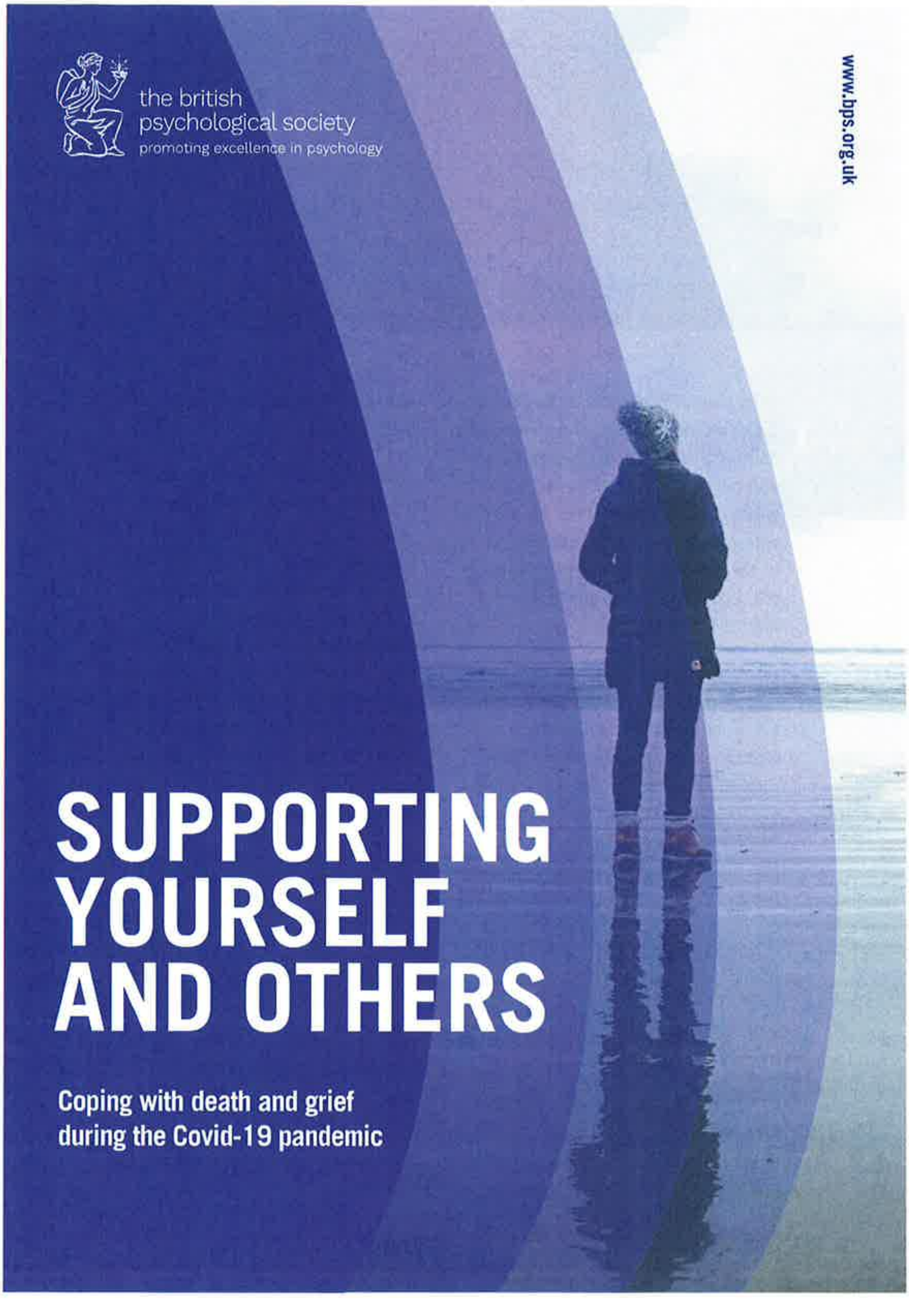
[4] Duffy, F. & Richardson, J. (2020). *Supporting Carers and Care Staff to Understand and Respond to Changes in Behaviour in People with Dementia During the COVID-19 Pandemic.* Northern health and Social Care Trust. http://www.northerntrust.hscni.net/clear

the british
psychological society
promoting excellence in psychology

St Andrews House,
48 Princess Road East,
Leicester LE1 7DR, UK

☎ 0116 254 9568 www.bps.org.uk info@bps.org.uk

6. Supporting yourself and others: Coping with death and grief during the Covid-19 pandemic

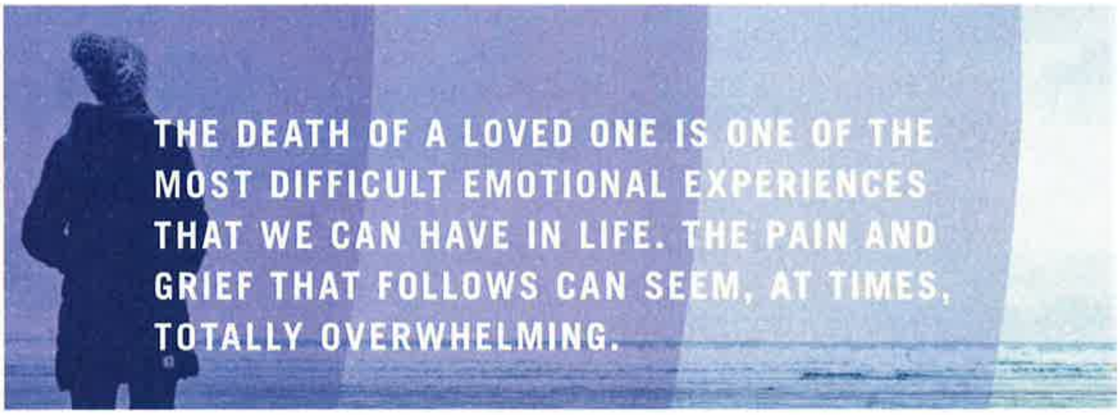


the british
psychological society
promoting excellence in psychology

www.bps.org.uk

SUPPORTING YOURSELF AND OTHERS

Coping with death and grief during the Covid-19 pandemic



THE DEATH OF A LOVED ONE IS ONE OF THE MOST DIFFICULT EMOTIONAL EXPERIENCES THAT WE CAN HAVE IN LIFE. THE PAIN AND GRIEF THAT FOLLOWS CAN SEEM, AT TIMES, TOTALLY OVERWHELMING.

Grief is often portrayed as one feeling, but it includes a range of emotions and reactions which affect how we think and how we behave. It is personal and will vary depending on your relationship with your loved one, the circumstances of the death and the experiences after the death. Grief often continues long after the death that triggers it.

Although extremely painful, grief is a normal response to any loss and is a way of helping us heal. While life may never be the same again, grief helps us readjust and cope with life without our loved one. It helps us find ways of maintaining our bond with our loved one when they are no longer physically present.

Being bereaved can be an extremely lonely time. Talking with friends and family can be one of the most helpful ways to cope after someone close to us dies.

One of the particular challenges of loss during the Covid-19 pandemic is that increasing numbers of people and households are being told to self-isolate or socially distance from friends and family.

This may mean you find yourself physically alone during this time, which can increase your feelings of loneliness and abandonment. Or you may be isolating as a family together, which may be supportive at times but may also make tensions and arguments bigger and more upsetting. Children and teenagers may find not being able to be with their friends difficult, and families may find keeping them occupied more challenging when also dealing with their own emotions.

As well as the emotional challenges, many practical considerations may arise, such as getting help with meals and shopping, as family and friends may also be isolating or preoccupied with their own family's situation.

Grief at any time is difficult and painful, and whilst Covid-19 may present additional challenges to the process, you will also experience all of the normal pain of loss and separation.

WHAT FEELINGS AND THOUGHTS MIGHT YOU EXPERIENCE AFTER THE DEATH OF YOUR LOVED ONE?

People who have experienced the death of someone close often describe experiencing some or all of the following feelings and thoughts. The social distancing measures required due to Covid-19 may also result in additional feelings and thoughts.

Shock, numbness or disbelief, especially immediately afterwards when people often report difficulty accepting or believing what has happened. This may be especially true during the pandemic, when you may not have the opportunity to see your loved one at the time of death or afterwards.

Anguish and despair, which can be accompanied by real pain and physical heartache as the reality of the loss sinks in. This may be increased as a result of not being able to have a full funeral during the pandemic. You may feel that the death has not been formally marked, that the person hasn't 'had the send of they deserved'. It does not give a sense of 'closure' nor brings community support.

Anger and irritability and the associated questioning of 'Why did this have to happen?'. This can include feeling that the death was untimely (even if expected) because it has been caused by the pandemic. This may also arise from feeling like the death of an older person is considered less important than for younger people during the pandemic. Anger can result in feeling that someone is to 'blame' for the death. For example, oneself for infecting the person, or people who are not social distancing, and government policies.

Restlessness or agitation, which are some of the typical physical side-effects of grief. For example, trouble sleeping or difficulty concentrating.

Longing or yearning for the person who has died. This normal part of grief is often associated with thinking that they have seen or heard the person who has died, and while this can be an upsetting experience, it should not cause alarm.

Loneliness, even when surrounded by others. This may be increased by being in isolation or having more limited contact with family and friends due to the restrictions in place.

Guilt, for things they may have/have not said or done. There can also be guilt that you are still alive when your loved one has died, or that you feel relieved that a loved one has died after a long illness or suffering. This may be especially true during the pandemic where a loved one may have had to go into intensive care, despite having indicated they wanted to die at home; or the person not being able to return home after recovery from Covid-19 due to existing or new health concerns.

Worry or fear for what lies ahead. There may be ongoing worry about your own health, or for other family members concerning Covid-19 infection. This may delay the reality of your loss due to being distracted by worries for others.

Deep sadness as you miss the one you love.

HOW MIGHT YOUR BEHAVIOUR CHANGE AS A RESULT?

How feelings are expressed varies from person to person, but it is very normal for feelings to change suddenly without warning. Some people liken this to being on 'an emotional rollercoaster'. Other people describe how their behaviour changes too. For example, people who are normally outgoing may start to avoid family and friends. The desire to talk constantly about the loved one may change to not being able to mention their name. Some people get comfort being somewhere that they associate with their loved one, while others will avoid such places as they are too painful.

Given the global impact of Covid-19, it is hard to escape from information about its impact and the losses that others are experiencing. Activities such as watching the news on TV, reading the papers, and spending a lot of time scrolling and reading things online may bombard you with information that will trigger your own feelings of sadness. You may feel overwhelmed by the wider losses and need to take some time out from such information in order to concentrate on looking after yourself and your own loss. This can make you feel guilty, but remember to be kind to yourself. In grief, you can only do the best you can.

Grief affects not just our emotional wellbeing, but can have an impact on physical health as well. You may notice changes in your sleep and appetite. It is normal to feel tired, often simply because of the intense emotions and stress experienced. While this may increase your need for sleep, you may experience disrupted sleep and struggle to have an uninterrupted night's rest.

Often people report a fear of sleeping because waking up is like being bereaved all over again. Your sleep should improve in time and of its own accord, but if it causes you concern, speak to your doctor or other health care professional who will be able to offer you further help and advice.

It can be common to see, hear or feel the presence of someone who has died. This can be more common in the case of traumatic bereavement and may cause particular distress if you are now isolating in the same location where your loved one died, or where you are constantly reminded of their illness. It is important not to be frightened if this happens. Phoning someone and checking in about your experiences can really help.

Other changes that you may notice include:

- Fatigue or tiredness.
- Being more prone to colds and minor illnesses. This may cause increased anxiety when you are more vigilant to worries about infection.
- Losing enthusiasm for your normal activities.
- Forgetfulness and difficulty concentrating.

Grief can have an impact on physical health as well as emotional wellbeing.

HOW MIGHT YOU COPE WITH BEREAVEMENT?

Each person will cope in their own way and it is important to know that there is no 'correct' way to grieve: for example, members of the same family may respond to the same death in different ways. This can sometimes leave relationships within families tense and strained. People often want to know for how long they should grieve. This will differ from person to person and adjusting to bereavement may take time. Your feelings may also ebb and flow.

You may find that you are initially kept busy with tasks such as arranging the funeral or sorting out your loved one's legal and practical matters. The pandemic means that some of the usual practices that help keep us distracted and busy in the first few days are restricted, meaning that your emotions may be speeded up.

After this, you may notice that you begin to feel worse instead of better. This is also very normal, as it may be that the full impact of the bereavement is only beginning to register.

Your experience and response to bereavement may be influenced by your culture, faith community or belief group. For example, you may believe in life after death and find religious or spiritual ceremonies comforting. Equally, you may have no religious beliefs and may want to mark the death in a very individual way, for example, having a remembrance gathering in a place that was special to the person who has died. The pandemic may mean that it is difficult to do things exactly as you or your loved one might have wished and it is important to look at alternative ways of remembering, or acknowledging that some wishes will need to wait for a later day.

> Members of the same family may respond to the same death in different ways.

WHAT CAN HELP?

You may find that you can cope by yourself; however, you may need the support of others. This can come from your family and friends, from other sources such as your local community or faith/belief group or perhaps from a health/social care professional. While you may appreciate some quiet time by yourself, it can be helpful to avoid withdrawing from other people.

Keeping in contact can take many different forms, and at this time of physical isolation, you and those around you can use alternative ways to prevent social isolation. Finding new ways to communicate may feel like an additional burden when you already feel exhausted and overwhelmed. However, it is worth pursuing these new ways of contact, as they will help keep you connected with others who love you and are concerned for you.

Because we carry many beliefs about online communication being inferior to in-person interaction, it surprises many people to learn that online interaction can be very effective in helping us to feel close to others, to give and receive social support, and to maintain existing bonds with friends and family. Seeking practical and/or emotional support – remotely or otherwise – is not a sign of weakness.

The pandemic may make it easier to become more isolated and withdrawn, when your energy and interest in connecting with others is low. It may be additionally important to help yourself connect by having set times to link with family and friends and encourage yourself to engage even when you don't really feel in the mood.

It is important to make some time to care for yourself. Returning to normal activities can help you to re-establish your routine. It is important to eat regular meals and take adequate rest so that your body can keep going. These steps will help you to feel more in control. Other activities such as taking some light exercise or doing something relaxing, such as taking a bath or listening to soothing music, may be beneficial.

It's important to make some time to care for yourself.

SOME OTHER HELPFUL SUGGESTIONS

Allow yourself time to grieve. Remember that special times, such as anniversaries, birthdays or Christmas can intensify feelings of grief after a person has died. You may benefit from extra support at these times.

If you feel like crying, don't prevent yourself from doing so. This is a normal way to release your feelings and is not a sign of weakness.

It may be helpful not to rush into decisions about your loved one's possessions and personal effects.

It can be useful to delay big decisions, such as moving house, so that you do not commit to making a change that you may not have had enough time or space to consider.

Try to stick to a healthy diet and engage in some form of exercise. Avoid unhealthy practices and dependencies such as: fast food, alcohol, medicine, drugs etc. which negatively impact on overall health and wellbeing.

As time passes, you will be reassured that any worries you had about forgetting your loved one are unfounded and that they will always be an important part of your life and memories. Keepsakes, such as photographs or other possessions, may be painful to look at early on, but can provide much comfort in the future.

If the intensity of your feelings adversely affects your daily life, do not hesitate to contact your GP.

COMPLICATED GRIEF

When the circumstances surrounding the loss are unique, this may result in 'complicated grief'. This can result in you feeling like you cannot bounce back and returning to your normal routine and responsibilities is impossible. The current pandemic presents a number of quite unusual circumstances which may result in additional thoughts and emotions (as outlined on page 2).

Complicated grief leaves the person who has been bereaved feeling stuck and in a struggle to cope with the emotional impact of their grieving.

As time goes on, the attempt to cope with these feelings can begin to have a long-lasting negative influence on normal day-to-day living. For example, daily tasks may become impossible and communication with close family and friends is difficult. In the long term this can contribute to your mental and physical health wellbeing.

As outlined above, if you feel that the intensity of your feelings affects your daily life, do not hesitate to seek support and contact your GP.

SUPPORTING SOMEONE WHO IS GRIEVING

People frequently worry about saying the wrong thing to someone who has experienced a loss and can avoid mentioning the death or making any reference to the person who has died. This often shows that a person is trying to be considerate, but it is important to remember that the bereaved person may be feeling lonely and your concern may help them to feel cared for. It can be helpful to pause before speaking and think about how the person who is grieving might hear what you are planning to say: for example, some people might find the phrase 'he has gone to a better place' more upsetting than comforting. It is often useful to remember that simply listening can be the most helpful thing to do.

OTHER WAYS OF BEING SUPPORTIVE

Acknowledging the death, for example, by sending a card or letter, or by conveying your condolences in person. This is particularly significant for losses during the pandemic. The normal visits to the home, attendance at funerals cannot happen, so it is important to ensure that you acknowledge the loss in different ways. We can worry about 'bothering' people, but often, it is the lack of acknowledgement that can cause the most hurt.

Spending time with the person who is grieving can provide comfort, although remember to check with them if they need some time alone. The support that you may give can be emotional, for example, listening to any worries they may have or memories/stories of the person who has died. Practical help could also be offered, such as doing shopping or cooking and serving a meal. This will be more difficult during current circumstances, so you may need to consider phoning or using social media to connect more frequently.

Understanding that if the person is expressing strong feelings, such as anger or irritability, they may not be intending to hurt your feelings.

Respecting that people may have particular cultural or religious beliefs and traditions that differ from those you hold.

Remembering significant events, such as birthdays or wedding anniversaries, may be comforting to the person who has been bereaved. Your thoughtfulness may be needed long after the funeral. Be mindful of how the person may wish to remember the event as special dates can be extremely difficult for them.

Following through with any offer of support, however, be aware that the support needed and your capacity to provide it, may change over time.

Being mindful about the impact that the bereavement may have had on you. Remember that it is okay to recognise and take care of your own needs.

FURTHER RESOURCES

CRUSE Bereavement Care I www.cruse.org.uk I 0844 477 9400

The Compassionate Friends UK I www.tcf.org.uk I 0845 123 2304

Winston's Wish I www.winstonswish.org I 08452 030405

The WAY Foundation I www.widowedandyoung.org.uk I 0300 012 4929

Survivors of Bereavement by Suicide I https://uksobs.org I 0844 561 6855

the british
psychological society
promoting excellence in psychology

The British Psychological Society is a registered charity which acts as the representative body for psychology and psychologists in the UK. We support and enhance the development and application of psychology for the greater public good, disseminating our knowledge to increase public awareness.

St Andrews House,
48 Princess Road East,
Leicester LE1 7DR, UK

☎ 0116 254 9568
🖵 www.bps.org.uk
✉ info@bps.org.uk

BRE30a I 27.04.2020

7. COVID-19 & Mindfulness: Resources for Health & Care Staff

The
Mindfulness
Initiative

COVID-19
& Mindfulness

Resources for Health & Care Staff

Thank you

In this crisis we owe you huge gratitude for your work caring for the health and wellbeing of people who need it. Whatever your role, this needs courage, dedication and humanity.

Many members of the public are anxious and stressed. For you, putting your own health at risk to support others, this can also be true.

Here are some resources on mindfulness practice. Many people find these practices, short or long, help them to deal with events that challenge their mental wellbeing. Please share freely with colleagues who might benefit.

If these help any one of you working under these unprecedented pressures that is enough.

Thank you again.

Why Mindfulness can help

Mindfulness practices can help people who experience emotional exhaustion, burnout, stress, psychological distress, depression, anxiety, and other problems. They can help improve self-compassion, the quality of sleep and improve relaxation.

Mindfulness training has also been used in high stress & trauma-prevalent public services with working conditions that require staff to perform a wide range of emergency duties in unpredictable environments.

It didn't matter what practice I did on a daily basis as long as I did one. I think this can be classed as the emergency approach – the breathing exercise as an anchor, the mantra that we STOP, BREATHE, REFLECT and CHOOSE as part of our daily life. Time will allow us then to focus on the deeper practices – for instance the ability to fall asleep when we need is often linked to the Body Scan, the ability to fight anxiety or panic attacks, to the Breathing Meditation. In short it is about being in the present and not focussing on the past which we cannot change nor the future which we cannot predict.

- Tim Boughton, Advisor to the Army on Mental Health, after 20 years in the military serving many of those on operations around the world

In times of uncertainty, our internal threat/protection system becomes more activate, especially when we focus on the caring of others. Unless we take care of ourselves, our energy is depleted. By taking the time to PAUSE, BREATHE and ask 'WHAT DO I NEED IN THIS PRESENT MOMENT?' we can be more present and respond rather than react. This is an act of kindness to ourselves.

- Dougie McPhail, Mindfulness Teacher to Scottish Ambulance Service, NHS and police personnel

Mindfulness Resources

Space for Health Workers

Breathworks free online 'virtual quiet space' for healthcare workers is a space to give you some mindfulness tips, guided practices, including weekly live sessions and video responses to questions. It is a peaceful 'virtual house' that you can repeatedly visit when you have a few moments to recharge and recuperate.

Short Practices

Even a few minutes can help in a time when you are feeling very high stress or emotion

- 1 minute Breathing Space (Breathworks)
- 90 Second Mini meditation (Finding Peace in a Frantic World)
- 3 Minute Breathing Space audio or video (MiSP/Oxford Mindfulness Centre)

- 3 Minute Coping with Difficulties (Bangor Centre for Mindfulness Research & Practice)
- 4 Minute Breathing Practice (Oxford Mindfulness Centre)
- 4 Minutes Feeling as Safe as You Reasonably Can (Dr Rick Hanson)
- 5 Minute Tension Release & other meditations (Breathworks)
- 5 Minute Chocolate Meditation. (BBC Mind Set Meditations)
- 9 Minute Befriending and Compassion for Self and Others (Finding Peace in a Frantic World)
- 7 Minute Mountain Meditation. 15 Minute Body Scan & other meditations (Free Mindfulness)

COVID-19 specific videos and podcasts

Dr Jud Brewer daily videos on Corona Virus Anxiety & why short mindfulness practices create our mental health hygiene

The Short Pause (with thanks to NHS Fife Going Beyond Gold)

Take regular short 2-3 minute pauses as often as you can during the day with 4 key steps

- Breathe

Take a few deeper breaths than normal – a long slow in breath and a long slow out breath - pay attention to your in-breath, all the way in – and your out-breath, all the way out. Feel a sense of letting go on the out-breath.

- Ground yourself

Feel your feet on the ground – notice any sensations like tingling or heat or cold. Paying attention to your feet takes your attention away from thoughts and difficult emotions.

- Smile

You may not feel like smiling, but doing it will automatically relax tension in your body – and it may light up someone else's day if they see you.

- Notice

Take notice of one thing you can be grateful for, right now in this moment, e.g. help from others, comfy bed, taste of tea or coffee, message from a friend, daffodils, etc.

Online Sessions

Oxford Mindfulness Centre is offering Free Weekly Online Mindfulness Sessions via Zoom (now extended to up to 500 participants). If the timing doesn't fit with your work, each session is available as a podcast afterwards

The Mindfulness Association is offering a Free Daily Online Meditation via Zoom at 7pm

Vidyamala Burch of Breathworks is offering a weekly Facebook live meditation on Tuesdays at 7 pm

Free open weekly guided mindfulness sessions via Zoom with Ed Halliwell Tuesdays at 6pm (register here)

Gaia House is offering online practice sessions on different weekdays and at different times

A Mindful Leader is a USA organisation offering free online weekday meditation and support sessions and resources

Children may well be anxious at this time, particularly if their parents are working in health or care roles. Mindfulness in Schools is offering a Sit Together every weekday at 11am for children & young people accompanied by an adult and Tuesdays and Thursdays at 7.30pm

Bubbles and Flashlights is offering Mindfulness sessions by zoom for children and for young people

Apps

The popular Headspace App is offering extended free content including Weathering the Storm meditations during the COVID-19 crisis. For NHS healthcare workers they offer Headspace Plus. Visit headspace.com/nhs and enrol using your NHS email address.

Calm, another very popular app, has many free resources for this crisis period, including help for sleep and resources to help children

Insight Timer has thousands of free meditations of many types freely available as well as calming music recordings

The Healthy Minds App is now free for individuals

Liberate is a free meditation app made by and for the Black and African Diaspora

MindPilot is a new free app with a mindfulness course by experienced mindfulness teachers Tessa Watt and Vishvapani Blomfield

Sites with many free resources

Free Mindfulness Project COVID-19 links you to up talks and online practice offered during the crisis by many leading mindfulness teachers.

Free Mindfulness Project Resources links to free downloadable meditations of different lengths.

Bangor University Centre for Mindfulness Research and Practice offers many mindfulness meditations of varying lengths, including some in Welsh Language, plus some yoga tutorials.

Center for Mindful Self-Compassion 10 Self-Compassion Practices for COVID-19 and related audio meditations by Chris Germer.

The Mental Health Foundation has a range of podcasts, including meditations, relaxation techniques and breathing space, to help manage stress.

The Mindfulness Network for People of Colour has links to free resources and can link you to group online meditations in the UK and US.

City University Centre for Excellence in Mindfulness Research will be sharing a wide range of resources publicly.

Courses

Breathworks is a longstanding provider of mindfulness training courses, including online. They have introduced a free online course for people isolating at home during the COVID-19 crisis. A special area with resources focused on health staff will be live soon.

Monash University has been providing mindfulness and wellbeing training for students for many years, starting with medical students. Its two online courses run for free but materials are available long term for a paid upgrade. Monash/FutureLearn Mindfulness for Wellbeing and Peak Performance is currently open. Maintaining a Mindful Life extends this but it not currently open.

BeMindfulOnline is a well established online mindfulness course with a good evidence base, recommended by the NHS Apps library. It has a £30 charge, unless you live in London where it is free via the Good Thinking website.

Books

There are many excellent books about mindfulness. Here are just a few that focus on teaching mindfulness practice:

Mindfulness: A practical guide to Finding Peace in a Frantic World (Book & CD) Mark Williams & Danny Penman

Mindfulness for Health: A practical guide to relieving pain, reducing stress & restoring wellbeing (Book & CD) Vidyamala Burch & Danny Penman

A Mindfulness Guide for the Frazzled, Ruby Wax

Mindfulness for Women (Book & CD) Vidyamala Burch & Claire Irvin

Health and Mindfulness

Mindfulness affects many bodily aspects of health and also how we think about our response to health.

Mindfulness training helps us cope with distress and disability in everyday life, as well as under serious stress.

Many qualities strengthened by mindfulness practice help our own health self-management:

- Compassion & self-compassion - important for preventing, recovering or reducing depression or suicidal thoughts
- Observing the transience of thoughts - reducing stress-induced intrusive thoughts, sleeplessness, emotional reactivity, anxiety, suicidal thoughts
- Breathing space practices - reduce intrusive thoughts, sleeplessness, emotional reactions, anxiety, blood pressure, panic attacks
- Sense of wider connection - helps cope with loss, life events, diagnoses, trauma, loneliness
- Being in the present moment - reduces fear of the future or anger & regret for the past
- Attention practice– witnesses our emotional responses, helping us managing pain or fears
- Stronger mind-body connection – increases awareness of the body, how we treat it and its changes

Health Education England's NHS staff and Learners Mental Wellbeing Commission cited research showing mindfulness practice reduced stress, anxiety and distress, increased empathy and could be of benefit to help doctors to cope with work pressures.

More information on Health, Wellbeing and Mindfulness

Mindfulness APPG hearing on mindfulness in high stress & trauma-prevalent public services (ambulance, police and armed services)

"You are not alone in feeling the way you do and we shouldn't be frightened to ask for help"
"I owe myself some time and compassion"
Scottish Ambulance Service Emergency Ambulance Personnel

About The Mindfulness Initiative

The Mindfulness Initiative grew out of a programme of mindfulness teaching for politicians in the UK Parliament. It provides the secretariat to the Mindfulness All-Party Parliamentary Group.

We work with legislators around the world who practice mindfulness and help them to make capacities of heart and mind serious considerations of public policy. We investigate the benefits, limitations, opportunities and challenges in accessing and implementing mindfulness training and educate leaders, service-commissioners and the general public based on these findings. Visit www.themindfulnessinitiative.org to find out more.

Getting in touch

If you have any questions, suggestions or other feedback on this document please get in touch by emailing info@mindfulnessinitiative.org.uk.

Supporting our work

The Mindfulness Initiative doesn't receive any public funding and in order to retain its neutral and trusted advisory position in the sector cannot generate revenue from competitive products or services. As such, we are entirely dependent on charitable gifts for sustaining our work. If you found this briefing paper helpful, please consider making a contribution.
Visit www.themindfulnessinitiative.org/appeal/donate to make a one-time or recurring donation.

Research & Writing: Jenny Edwards CBE

Sheffield, S1, United Kingdom
UK Registered Charity: 1179834

The Mindfulness Initiative

www.themindfulnessinitiative.org

8. Supporting Carers and Care Staff to Understand and Respond to Changes in Behaviour in People with Dementia During the Covid-19 Pandemic

Northern Health
and Social Care Trust

Supporting Carers and Care Staff to Understand and Respond to Changes in Behaviour in People with Dementia During the COVID-19 Pandemic

Dr Frances Duffy
Consultant Clinical Psychologist
&
Jill Richardson
Associate Psychologist

April 2020

We hope you enjoy this booklet which is designed to provide information to help support people with dementia during the COVID-19 pandemic.

Please talk through the suggestions with all family, carers and care staff who are involved in providing support.

We hope this booklet will help during this very challenging time and reduce stress and distress for both the person with dementia and those who love and care for them.

The original 'Supporting Carers and Care Staff to Understand and Respond to Changes in Behaviour in People with Dementia During the COVID-19 Pandemic' was developed by Dr Frances Duffy, Consultant Clinical Psychologist and Jill Richardson, Associate Psychologist, Psychology Of Older People Service, Northern Health and Social Care Trust (NHSCT). A special thanks to everyone who participated, including the NHSCT Dementia Home Support Team.

CLEAR Dementia Care © was originally supported by the Health and Social Care Board, Northern Ireland.

The most recent version of the document is available at:

http://www.northerntrust.hscni.net/CLEAR

For further information, please contact:

CLEAR.DementiaCare@northerntrust.hscni.net /
enquiries@innovations.hscni.net

Context

Government restrictions have been implemented to protect public health during the COVID-19 pandemic. Many care homes are closed to visitors and people living at home are advised to stay at home.

This document has been created to help carers and care staff to understand potential changes in the behaviour of people with dementia and offer suggestions on appropriate supports.

Carers and care staff

Carers and care staff will be worried about their own health, their family and those that they love and care for. They are likely to experience a range of emotions, for example feeling anxious, overwhelmed, upset or stressed. They may be worried that they have COVID-19, that they will pass it on to those they care for, or that they will become infected if the person they are caring for becomes infected. These fears are normal and understandable because this pandemic is not like anything we have experienced before.

If colleagues become unwell this can increase anxiety and a sense of vulnerability. There may also be staff shortages which impacts on workload and stress.

Talk to trusted friends and colleagues about how you are feeling. They are likely to be feeling the same.

Develop a routine with as much structure as possible to help you to feel a sense of control at a time where things may feel out of control.

Take breaks from caring and practice self-care by taking some time to do things that you enjoy.

People with dementia

There will be a significant change in routine for people living with dementia. People they love are no longer able to visit and they may not have access to the activities that they enjoy which provide meaningful occupation.

It is likely that there will be changes to staff who offer support if care staff who normally offer support become unwell or have less time to spend with the person if there are staff shortages.

This may result in fewer interactions for people with dementia. As a result, they could become bored and also anxious. They may not understand the need for physical distance, why changes in routine are happening or why the care staff that they have become familiar with are no longer there or less available.

The person with dementia will also pick up on the emotions of their carers. The anxiety that carers and care staff experience will also be experienced by the person with dementia.

When we are worried our natural tendency is to be with the people we love and feel safe with to seek comfort and support. This support may be less available during this time of restricted visiting. The emotional reaction to the changes and lack of understanding may result in in behaviours which carers can find difficult to understand.

Isolation for people with dementia

There is a significant challenge for people with dementia who need to be isolated from others because they have COVID-19 or because others are infected. This affects both the person and also those who care for them and offer support.

The person may not understand that they need to stay in their room. They may be confused and also lonely. Purposeful, meaningful activity will reduce the distress and reduce their need to leave their room for company or occupation.

Meaningful Occupation

Care staff are extremely busy and there is the risk that increased pressure and workload means that activities are reduced. Maintaining occupation and social connection is even more important during this time of increased stress for everyone. This does not mean that busy carers and care staff need to do more, but they may need to do things differently.

When we become bored we look for something to do. The same is true for a person with dementia. The challenge is the person with dementia may be unable to tell us what they want or need. If they are stopped by a carer when trying to find something to do, it could lead to behaviour that is interpreted as verbal or physical aggression.

Impact of Personal Protective Equipment

During the COVID-19 pandemic staff may need to wear protective equipment or masks. This could be frightening for the person with dementia. This also means that they may no longer recognise the carers or care staff that they are familiar with, who are offering support.

It may be helpful to laminate your name and a picture of your role attached to your clothing or on a string around your neck. This could be cleaned frequently.

If you are wearing a mask, the person will not be able to see you smiling and may find it more difficult to pick up on body language. Laminate a smiley face and attach this to your clothing or carry it with you. This may help the person to feel safer.

Contents

Physical Health

Changes in physical health contribute to changes in behaviour and emotional wellbeing. The following should be considered but this is not an exhaustive list.

- Is the person in pain?
- Do they have an infection?
- Are they experiencing a delirium?
- Are they dehydrated?
- Are they constipated, incontinent or need to use the toilet?
- Do they wear glasses and hearing aid, are these up to date and working?
- Does their medication need to be reviewed?
- Do they have any long term health conditions which need to be reviewed?
- Are they hungry, thirsty, or too cold or hot?

Understanding behaviour and offering support

All behaviour is a form of communication and is often driven by need. The challenge is that the person with dementia cannot always tell us what they need.

The following sections include examples of behaviours that the person may engage in and, at times, carers and care staff may not know how to respond.

In addition to using the suggestions on how to respond to the behaviour, it may also be helpful to look for patterns. Are there particular times in the day when the person engages in a specific behaviour?

Use CLEAR Dementia Care © (Duffy, 2016, 2019) Behaviour Record Charts to identify patterns in behaviour. If you know when a particular behaviour is likely to happen you can put strategies in place to support the person and meet their needs at these times.

Communication

When talking about COVID-19 with residents, use communication cards to help you (see http://www.aphasiafriendly.co/covid-19-accessible-information.html)

The person with dementia is likely to mirror your mood and behaviour. Fear can be contagious. Try to remain calm, smile and remain positive when talking or offering support. Even if you are wearing a mask, the person can see the smile in your eyes.

- Every time you meet the person, say hello, tell them your name and what your role is. "Hello Sadie ……..It's Clare ………I'm the nurse"
- Show them your name, picture of your role and the smiley face if you have these.
- If the person wears a hearing aid or glasses make sure they are wearing them to help with communication.
- Use short, simple sentences.
- Give the person time to process what you have said and respond.
- Listen to what they are saying.
- Give positive instructions 'Shall we go here?' instead of 'Don't go there'.
- Their reasoning may be affected by dementia. Arguing, disagreeing or correcting may lead to frustration.

Supporting Meaningful Occupation

How we spend our day affects how we feel and how we behave.

Activity gives our day structure, occupies us and gives purpose and meaning to life.

- Continue to offer a predictable routine each day with a variety of activity to help provide a sense of safety and security.
- Write the daily plan on a white board that is in view. Tick off each activity when it has finished.
- Follow guidelines on hand washing and ensure activity items are thoroughly cleaned before and after use.
- Support the person to stay connected with family and friends as much as possible using Phone, WhatsApp call, video, audio note, Skype and Zoom apps.
- Ask the family to send letters, card, photographs, voice and video messages and support the person to access these at regular intervals.

In a care home, it may be helpful to offer more group activities. Maintaining guidelines for physical distance, if a group of residents are in the lounge engaged in an activity, this may free up time for the remaining staff to complete personal care tasks with other residents. If the residents are engaged they are less likely to seek staff.

Focus more on doing the activity rather than the end result. Support residents to watch if they don't want to take part. Below are examples of activities but this is not an exhaustive list:

- Most people enjoy singing and this has a positive impact on mood.
- Offer each resident a balloon to play with.
- Play skittles or bowls with a plastic ball, cleaned with disinfectant wipes between each person.
- Choose some objects and pictures or photographs of famous people and engage in reminiscence.

- Recite proverbs and poems from childhood for reminiscence. Use a white board to help people remember the proverb or poem.
- Play music and ask residents to "name that song".
- Play a game of colour bingo.
- Paint, colour, draw or make cards.
- Set up a gardening station at a table.
- Offer some activities that do not require active participation, such as listening to music or watching TV, a short audio book.
- Steam concerts from YouTube.

Examples of other activities can be found at:

http://napa-activities.co.uk/membership/free-resources#things
https://musicmemories.bbcrewind.co.uk
https://www.rcot.co.uk/about-occupational-therapy/living-well-care-homes-2019
https://remarc.bbcregind.co.uk

For people who are in self isolation, living at home or when individual activity is being supported in addition to the activities above:

- Check in with the person frequently to see how they are and engage in brief conversation.
- The person may need help to start an activity.
- Try a range of activities to see what they enjoy doing.
- Try to create a rummage box.
- Offer colouring or puzzles on paper or on a tablet or computer.
- Involve the person in tidying, cleaning or sorting cupboards in their room where possible.
- Offer photographs, pictures, books and magazines.
- Support the person to go outside for a walk if possible.

There are different views on the use of dolls and children's toys. If used in the right way, a doll or a soft toy can meet the needs for comfort and attachment and give the person the opportunity to nurture and protect. This may be of particular benefit when the opportunity for engagement with family and friends is not possible.

A doll or soft toy can also provide the opportunity to increase communication between the person and their carers.

Asking to go home

The person may not recognise the people or things around them as familiar. They may be confused and anxious about where they are.

Home is not just a building. It's a feeling of safety and security, and the people and memories associated with the building.

When someone asks to go home they are looking for the feelings of comfort, safety and security that home brings. If family and other familiar people are not visiting or there are changes in staff, the person may experience this even more.

Support:

- Telling the person that they are at home may add to their confusion and distress.
- Ask if they are missing their son/daughter/husband/wife/significant other.
- Engage them in conversation about that person.
- Support them to look at photographs if available. This may help the person to experience familiarity, connection and feel safe and secure.
- If possible, ensure there are personal objects and photographs in their room.

Attempting to leave home

The person may not recognise where they are and want to go home. They may believe they have somewhere important to be, for example going to work or collecting children from school.

They may miss and worry about family members or significant others, especially as they have not been able to visit.

If they are prevented from leaving, they will worry about what will happen and their level of distress will escalate.

Support:

- Asking the person to come and sit down or telling them they cannot leave is unlikely to help.
- Find out where the person wants to go.
- Acknowledge how they might be feeling, for example, "You're worried about your children ……Let's see if we can find out where they are"
- As you walk with them, ask them to help you to do something.
- Purposeful activity will reduce the person's need to leave.
- If the person is asking about their children or family they may be missing them. Support them to look at photographs of family if available.
- If the person is asking to go to work, tell them that they do not have to go to work today but you need them to help you with a job around the home.

Asking for family members or significant others

A person with dementia may have a poor concept of time and feel like they haven't seen family members for a long time. This will be even more difficult during a time when family cannot visit. Where possible, maintain contact by phone, or video calls.

When they ask about someone it means they are thinking about that person and may be missing them.

Sometimes residents ask for dead family members and it can be difficult to know what to say. They may not remember that they have died, even if they attended the funeral.

Support:

- Ask if they are missing that person.
- Tell them when the person last visited. Explain where the person is now, for example, home or at work.
- Spend time reading the letters and cards, listening to voice messages or watching video messages if family and friends have sent these.
- Look at photographs of family and friends and engage in conversation about them. Help the person to focus on happy memories and good times.
- If appropriate, explain that family/friends cannot visit because of the COVID-19. Use communication cards from http://www.aphasiafriendly.co/covid-19-accessible-information.html to help.
- If the person is occupied with activity they are less likely to become distressed.
- When a person asks about a dead relative, do not give them inconsistent messages. Remind them that the person has died. Tell them you understand it is a sad time and you know they are missing the person.
- If telling the truth causes significant ongoing distress, do not continue to remind them that the person has died.

Personal care

Because of their dementia, the person may not be aware that they need support with personal care and they may be confused and frightened about what is happening.

They may not know who you are or why you are in their personal space. They may be less likely to recognise you if you are wearing a mask. Strangers do not normally come into our bedroom and remove our clothing.

The person may feel embarrassed, cold or in pain.

They may behave in a way to defend themselves from what they perceive as an assault or to stop you from moving them and causing pain. This may be perceived as aggression.

Support:

- Say hello and tell the person who you are. Give them time to process what you have said and respond.
- If being supported by multiple carers, only one person should talk at a time.
- Hold out your hand and say “Shall I help you to get out of bed?” or “Shall I help you to get dressed?”
- Provide visual cues about what is happening. For example, show them the towel and face cloth.
- Support with upper body washing/dressing before moving onto the lower half.
- Encourage the person to be as independent as possible, for example, give them the cloth to wash their face and support them to choose an outfit.
- Slow the pace. If the person declines, give them time.
- Engage in conversation using short sentences to help them to feel safe.
- Keep the person covered as much as possible to keep them warm, protect their dignity and reduce potential embarrassment and distress.

Walking

When a person walks (sometimes referred to as wandering or pacing) they are either going somewhere, looking for someone, wanting to do something or simply want to get some exercise.

If a person sits in the same location for a period of time with no activity to engage them, they are likely to become bored, get up, walk and seek something to do. This will be more likely if the person has to stay in their room because of the need to self-isolate.

Support:

- When you see someone walking, ask them if there is something they need. If they cannot use language, pictures may help.
- Try activities that may be related to previous jobs, roles, routines and things they enjoyed doing.
- Be aware of the person's ability to attend and engage with the activity. They may need help to get started and the activity will need to be changed at times to reduce boredom.
- If possible go for a walk with them.

Sleep problems

Dementia can cause disruption of the sleep wake cycle. The person may fall asleep easily during the day but find it difficult to get to sleep at night. They may waken during the night or find it difficult to get back to sleep.

The person may get up in the night believing it is day time. They may dress for work, not remembering that they no longer work.

They may experience vivid dreams, nightmares or hallucinations, particularly in Lewy body dementia. Delirium, physical health problems and pain may also contribute.

Support:

- Assess for physical health changes which may be disrupting sleep.
- Orientate the person to the time throughout the day.
- Reduce daytime naps and avoid caffeine in the evening.
- Ensure there is good light during the day and it is sufficiently dark at night.
- Ensure the person's bedroom is not too cold or not too hot.
- Ensure their bed is suitable and they have comfortable night wear.
- If there is a risk of falls it may be appropriate to use a device to alert that the person is up.
- If the person experiences vivid dreams, nightmares or hallucinations at night, listen to them and provide reassurance.
- It can sometimes help to support the person out of their room for a short time before supporting back to bed.

Anxiety

Anxiety is an understandable response to the daily stress and distress the person experiences as they try to make sense of the world around them and meet their needs. Their anxiety may escalate during the COVID-19 pandemic as the person knows that something is wrong and is missing their usual routine and visitors.

Anxiety can make someone feel upset, irritable, cause difficulty concentrating and sleeping, cause them to sweat, feel dizzy and experience heart palpitations or panic attacks.

The person may seek frequent reassurance from carers, other residents or care staff.

Support:

- Telling someone not to worry or calm down usually doesn't help.
- Support the person to a quieter area if they are distressed.
- Talk to the person and ask them what is upsetting them. Acknowledge how they feel, for example "It sounds like you are feeling worried."
- A person with dementia may mirror and reflect your mood and behaviour. If you appear anxious, this may cause the person to feel even more anxious.
- Be patient with the person. A warm, positive and friendly approach will help.

References

Duffy, F. (2016). Look at all of me: A CLEAR model for dementia care, The Journal of Dementia Care, Vol. 24, No. 3, pages 27-30.

Duffy, F. (2019). CLEAR Dementia Care © : A Model to Assess and Address Unmet Need. Jessica Kinglsey Publishers.

Northern Health
and Social Care Trust

Appendix 1

Understanding Changes in Behaviour in People with Dementia during the COVID-19 pandemic Posters

Dr Frances Duffy
Consultant Clinical Psychologist
&
Jill Richardson
Associate Psychologist

April 2020

We hope you enjoy these posters which are designed to provide information to help support people with dementia during the COVID-19 pandemic.

You may find it helpful to print and laminate these posters and p;lace them in locations where all care staff, carers and families can see them.

We hope the posters will be helpful during this very challenging time and reduce stress and distress for both the person with dementia and those who love and care for them.

The original 'Understanding Changes in Behaviour in People with Dementia during the COVID-19 pandemic' was developed by Dr Frances Duffy, Consultant Clinical Psychologist and Jill Richardson, Associate Psychologist, Psychology Of Older People Service, Northern Health and Social Care Trust (NHSCT). A special thanks to everyone who participated, including the NHSCT Dementia Home Support Team.

CLEAR Dementia Care © was originally supported by the Health and Social Care Board, Northern Ireland.

CLEAR.DementiaCare@northerntrust.hscni.net / enquiries@innovations.hscni.net

Physical Health

Changes in physical health contribute to changes in behaviour and emotional wellbeing.

- Is the person in pain?

- Do they have an infection?

- Are they experiencing a delirium?

- Are they dehydrated?

- Are they constipated, incontinent or need to use the toilet?

- Do they wear glasses and/or hearing aid(s), are these up to date and working?

- Does their medication need to be reviewed?

- Do any long term health conditions need to be reviewed?

- Are they hungry, thirsty, or too cold or hot?

Appendix 1 Posters Contents

Behaviours

Communication

A person with dementia is likely to mirror your mood and behaviour.

Fear can be contagious.

Try to remain calm and smile when talking or offering support.

Even if you are wearing a mask, the person can see the smile in your eyes.

- Every time you meet the person, say hello, tell them your name and what your role is. "Hello Sadie ……..It's Clare ………I'm the nurse"
- Show them a laminated card with your name, photograph or the picture of your role and a smiley face if you have these.
- If the person wears a hearing aid or glasses make sure they are wearing them to help with communication.
- Use short, simple sentences.
- Give the person time to process what you have said.
- Listen to what they are saying.
- Give positive instructions: 'Shall we go here?' instead of 'Don't go there'.
- Their reasoning may be affected by dementia. Arguing, disagreeing or correcting may lead to frustration.

When talking about COVID-19, use communication cards to help you (see http://www.aphasiafriendly.co/covid-19-accessible-information.html)

Supporting Meaningful Occupation

How we spend our day affects how we feel and how we behave. Activity gives our day structure, occupies us and gives purpose and meaning to life.

- Offer a predictable routine each day with a variety of activity to help provide a sense of safety and security.
- The person may need help to start an activity.
- Try a range of activities to see what they enjoy doing.
- Focus more on doing the activity rather than the end result.
- Check in with the person frequently to see how they are and engage in brief conversation.
- Support the person to stay connected with family and friends as much as possible using Phone, WhatsApp, video, audio note, Skype and Zoom apps.

Examples of activity: music and singing, audio books, TV, gardening, colouring, painting, making cards, playing with balloons, cards or puzzles, rummage boxes, walking outside, reminiscence using photographs, pictures, books, magazines, skittles or bowls, bingo, reciting poems and proverbs, household tasks such as tidying, cleaning, sorting. The use of dolls and soft toys, if used in the right way, can meet the needs for comfort and attachment.

Anxiety

Anxiety is an understandable response to the daily stress and distress a person with dementia may experiences as they try to make sense of the world around them and meet their needs.

Their anxiety may escalate during the COVID-19 pandemic as the person knows that something is wrong and they are missing their usual routine and visitors.

Anxiety can make someone feel upset, irritable, cause difficulty concentrating and sleeping. It can also cause them to sweat, feel dizzy and experience heart palpitations or panic attacks.

The person may seek frequent reassurance from carers, other residents or care staff.

Support:

- Telling someone not to worry or calm down usually doesn't help.
- Support the person to a quieter area if they are distressed.
- Talk to the person and ask them what is upsetting them. Acknowledge how they feel, for example "It sounds like you are feeling worried."
- A person with dementia may mirror and reflect your mood and behaviour. If you appear anxious, this may cause the person to feel even more anxious.
- Be patient, a warm, positive and friendly approach will help.

Asking for Family Members

A person with dementia will miss family and friends who cannot visit during the COVID-19 pandemic. Where possible, maintain contact by phone, or video calls.

When they ask about someone it means they are thinking about that person and may be missing them.

Support:

- Ask if they are missing that person.
- Explain where the person is now, for example, home or at work.
- Spend time reading letters, cards, listening to voice messages or watching video messages if family and friends have sent these.
- Look at photographs of family and friends and engage in conversation about them. Help the person to focus on happy memories and good times.
- If appropriate, explain that family/friends cannot visit because of the COVID-19. Use communication cards from http://www.aphasiafriendly.co/covid-19-accessible-information.html
- If the person is occupied with activity they are less likely to become distressed

Asking to go Home

A person with dementia may not recognise the people or things around them as familiar. They may be confused and anxious about where they are.

Home is not just a building. It's a feeling of safety and security, and the people and memories associated with the building.

When someone asks to go home they are looking for the feelings of comfort, safety and security that home brings. If family and other familiar people are not visiting or there are changes in staff, the person may experience this even more.

Support:

- Telling the person that they are at home may add to their confusion and distress.
- Ask if they are missing their son/daughter/husband/wife/significant other.
- Engage them in conversation about that person.
- Support them to look at photographs if available. This may help the person to experience familiarity, connection and feel safe and secure.
- If possible, ensure there are personal objects and photographs in their room.

Attempting to Leave Home

A person with dementia may not recognise where they are and want to go home. They may believe they have somewhere important to be, for example going to work or collecting children from school.

They may miss and worry about family members or significant others, especially as they have not been able to visit.

If they are prevented from leaving, they will worry about what will happen and their level of distress will escalate.

Support:

- Asking the person to come and sit down or telling them they cannot leave is unlikely to help.
- Find out where the person wants to go.
- Acknowledge how they might be feeling, for example, "You're worried about your children……..Let's see if we can find out where they are"
- Gradually change the topic and ask them to help you to do something.
- Purposeful activity will reduce the person's need to leave.
- If the person is asking to go to work, tell them that they do not have to go to work today but you need them to help you with a job around the home.

Calling or Shouting Out

A person with dementia may call or shout out because they:

- Are in pain.
- Need something and have difficulty communicating what this is.
- Feel worried or frightened, lonely or isolated.
- Are bored and have nothing to occupy them.
- Are responding to a hallucination.

The person will continue to call out unless we respond to their distress and support them to meet their needs.

During COVID-19 people they may feel even more lonely or isolated, worried or frightened, and they may have less to occupy them due to a change in usual routine and activity.

Support:

- Telling the person to stop calling out is likely to increase distress.
- Find out what the person needs - are they hungry, thirsty, in pain, too hot/cold.
- If they are feeling frightened, upset or lonely, spend time listening to them and engaging in conversation to help them feel valued and cared for.
- Check in with the person at regular intervals. Let them know you are there.
- Offer a consistent routine with opportunity for activity.
- Where possible, support them to engage with others socially. Use phone and apps such as WhatsApp and Zoom to communicate with family and friends.

Delusions

A delusion is when a person believes that something is true when it is not true. For example, they may falsely believe that someone is trying to poison them, imprison them or steal from them, or that their partner is having an affair.

Support:

- It is usually not helpful to try to convince the person that what they believe is untrue. What the person is experiencing is real to them.
- Ensure the person is wearing their hearing aid(s) or glasses.
- Check for sounds that might be misinterpreted, such as noise from a television or an air conditioner. Look for lighting that casts shadows, reflections or distortions on the surfaces of floors, walls and furniture. Turn on lights to reduce shadows. Cover mirrors with a cloth or remove them if the person thinks that he or she is looking at a stranger.
- Offer reassurance that you are there and they are safe.
- Stay calm and listen to what they are saying.
- Support them to a quiet area as loud environments may increase distress.
- It may help to go for a walk or move to another room.
- Engage the person in conversation or an activity to distract from the delusion.

Following Carers

Sometimes a person with dementia will seek close proximity to carers. They may call after or follow the carer around or become upset when the carer leaves the room, even if it is only for a few minutes.

At times of loss, danger or stress, our need for safety and security is even greater. Being close to another person can help us to feel safe. This may be particularly evident during COVID-19.

Support:

- Help the person to feel safe by maintaining a familiar environment with familiar people and objects as much as possible.
- Listen to what the person is saying.
- Are they thirsty, hungry, need to use the toilet, are they in pain or discomfort?
- When you leave the room, tell them where you are going and when you will be back, for example, "I'm going to the kitchen…..I will be back in 15 minutes."
- Support the person to engage in activity, look at photographs, watch TV or listen to music while you are away.
- Check in with them at regular intervals to ask if they are ok.

If you are feeling stress as a carer consider:

- Are you getting any breaks from caring or do you need further support?
- Helplines and online support forums can help.
- Speak to family and friends via phone or video.

Hallucinations

Hallucinations are when the person experiences something that is not there.

- Visual hallucinations are seeing things that are not there. For example, the person may see people or animals.
- Auditory hallucinations are hearing sounds that are not real, such as a knocking sound or footsteps.
- Olfactory ("tasting") or tactile ("feeling") hallucinations are less common but can sometimes occur.

The person may experience a range of emotions such as fear, irritation, amusement or bewilderment. The person may respond to hallucinations, by talking or pointing and this can cause distress for carers.

Support:

- It is usually not helpful to try to convince them that what they are experiencing is not real.
- It is important to rule out a delirium with a sudden onset of hallucinations.
- If distressed, support thee person to a quiet area. Stay calm and listen to what they are saying. Offer reassurance that you are there and that they are safe.
- It may help to go for a walk, move to another room, or engage the person in conversation or activity to distract from the hallucination.
- It may take time for the person's distress to reduce.
- If you are concerned about the hallucinations seek medical advice.

Inappropriate Urination

A person with dementia may sometimes urinate in places other than the toilet or bathroom. This can feel embarrassing and frustrating for both the person and their carers.

Because of the person's dementia they may be:

- disorientated or unable to remember where the toilet is
- have difficulty getting to the toilet in time
- misidentify a cupboard for the bathroom
- be unable to ask for help with the toilet
- be embarrassed about having to ask for help
- be experiencing incontinence

Support:

- Do not draw attention to their incontinence.
- Signs that the person may need to use the toilet include:
  - Getting up from their seat, leaving the room or walking the corridor.
  - Entering other people's rooms or bathrooms.
  - Fidgeting with their clothing, waistband, belt or removing their clothing.
- Use pictures and word signs on the toilet doors.
- 20-30 minutes after meals or fluids, approach the person and say 'Shall I walk with you to the toilet?'
- If you are concerned about urinary incontinence or other physical health problem, contact the person's medical practitioner or continence service.

Looking for Occupation

Sometimes a person with dementia may go into other people's personal space, take or rearrange their belongings. Sometimes they may try to care for others, for example trying to feed them or give them a drink.

This can cause distress for other people if they do not want the person to be in their space, take their things or touch them. If the person is asked to stop or others refuse their help, the person may become confused and upset.

The person is most likely trying to help or looking for something to do.

Support:

- Thank the person for their help and gently direct them to another activity.
- Their life story may help to identify activities they enjoy to help them feel useful and valued, for example, jobs around the home.
- A consistent routine with a range of activities is important.
- There are different views on the use of dolls and children's toys. If used in the right way, a doll or a soft toy can meet the needs for comfort and attachment and give the person the opportunity to nurture and protect.

Low mood and Depression

Life changing events can trigger low mood and depression. COVID-19, the associated changes in visitors, routine and activity, and the feelings this can bring, may mean people with dementia are at increased risk of developing low mood or depression.

Some common symptoms of depression include:

- Loss of interest in previously enjoyed activities or hobbies.
- Lack of energy.
- Problems sleeping.
- Reduced appetite and weight loss.
- Changes in behaviour include wanting to be alone, restlessness, irritability, aggression, tearfulness and refusing support.

Support:

- Support the person to eat a healthy diet.
- Offer a consistent, predictable daily routine with meaningful activities including exercise.
- Spend time with them at intervals throughout the day.
- Support the person to tell you how they feel, if they can and want to.
- Focus on what they can do rather than what they cannot do.

Personal Care

Because of their dementia, the person may not be aware that they need support with personal care and they may be confused and frightened about what is happening.

They may be less likely to recognise you if you are wearing a mask. Strangers do not normally come into our bedroom and remove our clothing.

The person may feel embarrassed, cold or in pain.

They may behave in a way to defend themselves from what they perceive as an assault or to stop you from moving them and causing pain.

Support:

- Say hello and tell the person who you are. Give them time to process what you have said and respond.
- Hold out your hand and say “Shall I help you to get out of bed?” or “Shall I help you to get dressed?”
- Provide visual cues about what is happening. For example, show them the towel and face cloth.
- Encourage the person to be as independent as possible, for example, give them the cloth to wash their face and support them to choose an outfit.
- Slow the pace. If the person declines, give them time.
- Engage in conversation using short sentences to help them to feel safe.
- Keep the person covered as much as possible to keep them warm, protect their dignity and reduce potential embarrassment and distress.

Physical Aggression

For a person with dementia, the world can be a confusing and frightening place. With loss of independence, if the person is unable to communicate their needs, or if their needs are not met in a timely manner, this can cause further frustration.

They may be frightened and think someone has come into their personal space with the intention of hurting them or stealing from them. They may also be in pain.

If the person feels threatened they may attempt to defend themselves. This may cause them to hit out, kick, grab or hurt others physically.

Support:

- Offer support in a way that helps the person to understand what is happening.
- Respond in a calm and patient manner. This can be difficult if you feel the person is being aggressive but this may help to stop their frustration from escalating.
- Your body language, facial expression and tone of voice can help to reduce the emotion.
- If the person can understand, ask them what has upset them and try to support with what they need.
- Supporting the person to move to a different environment can help.
- When the person is feeling calmer, offer an activity, a walk or a cup of tea.

Refusing Medication

The person may not remember that they have specific health conditions so may not understand why they need to take medication. At times a person may refuse medication but, when it is offered a short time later they take it.

We all have different ways we like to take medication and it isn't always a pleasant experience.

Support:

- Find out how the person likes to receive their medication e.g. in their hand, in a medicine pot, on a spoon or with a specific drink.
- Encourage them to be as independent as possible taking the medication.
- Talk to the person for a few minutes before offering medication.
- Explain what each medication is for, for example, 'This tablet will help the pain in your legs'.
- Be patient and give them time.
- Think about when medication is offered. Sometimes it is unhelpful to provide medication when someone is eating, getting dressed or doing another task where they are already occupied.
- If they continue to refuse medication it is important to seek medical advice.

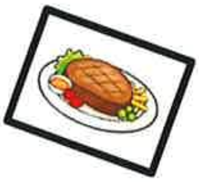
Refusing to eat or drink

The person may not be able to tell others they don't like the food or that it is too hot or cold.

If the person doesn't recognise where they live, or if they now eat with other people whom they don't know, this may cause anxiety or distress and they may not want to eat. If the environment is loud or busy this may also cause distress at meal times.

Support:

- Their life story will help to know their food preferences.
- Food and fluid intake charts can help to identify times they are more likely to eat and what food and drinks they prefer.
- Offer a choice (2 options), for example, "Would you like a sandwich or soup?". Pictures may help.
- Try to encourage the person to be as independent as possible.
- Give them time, say less and smile more.
- If the person is distressed, spend a few minutes talking with them and providing reassurance.
- If the person refuses, come back a while later and offer again.
- Provide smaller meals and snacks more frequently.
- Use coloured plates and bowls.
- Liaise with the person's GP, dietician and speech and language services as appropriate.



Repetitive questions and stories

When we talk to someone it is usually because we want to engage in social interaction.

When we ask a question it is usually to find out something we need to know or sometimes we just want to start a conversation.

When the person can't remember what happened recently or what is going to happen next, they may feel worried. For example: "Am I going to miss an appointment?" During COVID-19 they may ask more questions about where their family is or what is happening.

Because of their dementia the person will not remember that they have told the story or asked the question before, often multiple times.

Support:

- Telling the person that they have already asked the question or told the story is unlikely to help and may lead to an argument or cause distress.
- Listen to what the person is saying and answer in a consistent way.
- If they repeat the story, gently move the conversation to a different topic.
- If the person can read, write information about appointments or answers to common questions on a white board that they can easily see.
- Engage the person in an activity to take their mind off the story or question.
- A structured, predictable routine can help.

Sexually disinhibited behaviour

Many people with dementia continue to have sexual needs.

For some people, if they have a sexual thought, because of their dementia, they may be unable to control the urge to act upon the thought. The person might also:

- misidentify others as their husband/wife/partner
- misinterpret the actions of others, for example, support with personal care as a sexual advance
- be trying to get dressed and come out of their room in a state of undress.

Support:

- Check if the person is too hot, is in pain, has an infection or other physical illness which may be making them uncomfortable.
- Review medications for any side effects.
- If the person is in a state of undress, maintain their dignity.
- Refer to the person by their name and avoid using terms of affection like “pet”
- If the person is touching inappropriately or making sexualised comments, calmly tell them that you do not like that, do not become angry.
- If a person has something in their hands they may be less likely to touch.
- Change the conversation to a different topic or engage them in activity.
- Show a photo of their partner or family and engage them in conversation.
- Support the person to engage in social activities and build relationships with others to reduce loneliness and meet the need for social interaction.

Sleep Problems

Dementia can cause disruption of the sleep wake cycle. The person may fall asleep easily during the day but find it difficult to get to sleep at night.

The person may get up in the night believing it is day time. They may dress for work, not remembering that they no longer work.

They may experience vivid dreams, nightmares or hallucinations, particularly in Lewy body dementia. Delirium, physical health problems and pain may also contribute.

Support:

- Assess for physical health changes which may be disrupting sleep.
- Orientate the person to the time throughout the day.
- Reduce daytime naps and avoid caffeine in the evening.
- Ensure there is good light during the day and it is sufficiently dark at night.
- Ensure the person's bedroom is not too cold or not too hot.
- Ensure their bed is suitable and they have comfortable night wear.
- If there is a risk of falls it may be appropriate to use a device to alert that the person is up.
- If the person experiences vivid dreams, nightmares or hallucinations at night, listen to them and provide reassurance.
- It can sometimes help to support the person out of their room for a short time before supporting back to bed.

Smearing or eating faeces

Because of their dementia, the person may not be aware that they need a bowel movement. If they have experienced faecal incontinence or had an accident, they may be embarrassed and attempt to clean up. When doing this they touch and smear their faeces because of difficulties with coordination.

Faecal smearing may happen because the environment is understimulating and the faeces are something to touch or feel for sensory input.

The person may misidentify their faeces as a piece of food or other object. If they have reduced taste or smell sensations they may not realise what it is.

Support:

- Review the person's physical health.
- It is understandable to feel upset, shocked or embarrassed but patience and understanding is important. If the person becomes aware that you are distressed, this may cause them more embarrassment and distress.
- If the person wears continence pads, ensure these are changed regularly.
- Check that the person is not too warm or experiencing discomfort or itching.
- Making the room more stimulating can help – using light and light projectors, use diffusers and other pleasant smells, play music or other sounds, using sensory items e.g. fidget blankets.

Verbal Aggression

A person with dementia may not always have control over their emotions or what they say or do. If they are doing something and are told 'no, you can't do that', they don't understand that they have done anything wrong and are likely to be confused. They may shout because they don't understand why you are interfering in their business.

A person may be cross if they are experiencing pain, if they are frustrated about their difficulties, or if they are experiencing anxiety or low mood. It is difficult not to take this personally but it is important to remember that it is unlikely that the person is deliberately trying to upset others.

Support:

- Rule out pain or physical illness.
- Talk to the person to try to establish what they need and why they are upset.
- Remain calm and do not raise your voice.
- Use short phrases, say less and listen more when the person is upset.
- A positive facial expression and soft tone of voice can help.
- If you cannot find out what they need, offer them an activity, for example, to go for a walk or a cup of tea.
- Give the person space to calm down.
- Avoid using negative language or phrases such as 'No, you can't do that', 'That's bad/wrong' or 'Get out of there'

Walking with Purpose

When a person walks they are either going somewhere, looking for someone, wanting to do something or simply want to get some exercise.

If a person sits in the same location for a period of time with no activity to engage them, they are likely to become bored, get up, walk and seek something to do. This will be more likely if the person has to stay in their room because of the need to self-isolate.

Support:

- Offer a structured routine with a variety of activity.
- When you see someone walking, ask them if there is something they need. If they cannot use language, pictures may help.
- Try activities that may be related to previous jobs, roles, routines and things they enjoyed doing.
- They may need help to get started and the activity will need to be changed at times to reduce boredom.
- If possible go for a walk with them.

9. Mersey Care online links

Post Diagnostic Support Group Session 1 – tinyurl.com/PDSG1

Post Diagnostic Support Group Session 2 - tinyurl.com/PDSG2

Post Diagnostic Support Group Session 3 - tinyurl.com/PDSGSession3

Mindfulness Workshop – tinyurl.com/Mossley-Mindfulness

Self-compassion mindfulness practice – tinyurl/Self-compassionMeditation

Guided Mindfulness - tinyurl.com/MossleyGuided

More Mindfulness - tinyurl.com/MossleyMindfulness2

Understanding anxiety - tinyurl.com/MossleyAnxiety

Teaching sessions

Working with Carers Teaching session - tinyurl.com/CarerTraining

Adaptations to working with Older People - tinyurl.com/AdaptationTeaching

Working with Grief and loss - tinyurl.com/GriefTraining