



Restoring Relationships: The Recovery of Love, Connection and Family

**Toolkit for Families and
Relatives of People Living in
Care Homes**



Contents

Introduction	3
Family Involvement Plan guidance for families – “included not excluded”	4
Activities for families when short of time or anxious about reconnecting	8
Music helps dementia: How to harness the power of music during visits with loved ones	11
Creating a safe space	13
Communicating with care home staff	15
Going home checklist	17
Unresolved loss and grief – “Emotions without a home to go to”	18
Top tips to help manage feelings of unresolved grief and loss	19

Introduction



The global pandemic has left families feeling a physical and emotional separation from your relatives who live in care homes.

It led to a disconnection of relationships, love and support for a sustained amount of time. As families and relatives you experienced a void in your lives where the person used to be and all that went with loving and caring for them.

The use of “visitor” status and the provision of “visits” led to families feeling that the love, connection and vital care you usually share with your relative living in a care home got lost. Families felt left on the outside and not as involved in the day to day care of their loved one. It is a complex situation with many strong emotions, families and care home staff have faced long periods of uncertainty coupled with fear, stress and frustration. It has been a difficult time for everyone involved and you may have felt your relationships with your relatives and the care home staff have changed over that time. You may be looking for support to reconnect and restore these relationships; you may be looking for support to build new relationships as we move forward.

At the very heart of this project is family, love and connection.

Connection when you love and care for a person that you are separated from is such a fragile thing – it is what families hold on to dearly, it is what families try to nourish and protect for as long as they can and it is the one thing families fear losing the most. That loss is what is being felt most at the moment by everyone and the impact of that loss should never be underestimated or ignored.

This toolkit will support you to –

- Create a Family Involvement Plan – which recognises your shared history and the importance and equal value of your care
- Create and maintain safe spaces and safe conversations with care home staff
- Understand the feelings and thoughts of Care Home Staff and Managers
- Hints and tips around activities and ways to reconnect with loved ones (particularly if they have dementia and you are worried about deterioration in their condition)
- Understand and manage the feelings connected to the losses you have experienced
- How to reset after spending time with your loved one

Family Involvement Plan guidance for families – “included not excluded”



One of the biggest fears reported by families was the feeling of no longer being involved or part of their relatives care. One family member asked that it be looked upon as “shared care” and that they want to feel “included not excluded”.

This is some of the thoughts they shared:

“I have been her daughter for 62 years, I know my mum’s feelings and life experiences, please ask me what is best for her”

“The caring doesn’t stop just because they are living in a care home”

“What we offer to our families gets lost”

“Regard me as part of the team; don’t see me as extra work”

“Trust me and talk to me as if I work with you”

“Don’t see me as the enemy, we need to work together – I support the importance of the job you do”

We wanted to find a way to encourage that “shared care” as well as recognising and valuing what you as families and relatives contribute to the care of your loved ones, all the extra little things that you used to do with or for that person. If your family member moved into the care home during the pandemic and you haven’t been able to interact with staff as normally would have happened, it is vital to enable families to be able to explain and document what kind of things you would normally do with or for the person in the community and what you would still like to continue doing if possible.

We created a Family Involvement Plan (FIP). The FIP will enable you as families to illustrate the love, connection and care you usually share with your relative. It should compliment care plans and activity planning that

already exists in the care home. It should be flexible and adaptable as the needs of person change and their condition evolves. It will not act as a tool to blame and shame staff in care homes about what they are not doing – it aims to enhance the care already received and assist care home staff to develop care plans and activities for residents.

The key to the FIP is that it will provide person centred care in the truest sense of the word as it underpinned by love and connection between families. The FIP is underpinned by Maslow's Hierarchy of Needs¹ – and has the potential to meet both the basic level of needs and the next level of psychological needs of the residents. For families this is a high priority prolonged separation from each other may have led to the possibility in some cases (through no fault of families or staff) that the residents may not have had their psychological needs met

You should fill in the FIP yourself first and in partnership with your relative living in a care home. This may be more difficult if they have more advanced dementia for example and are not able to communicate as easily. In these cases you should fill in FIP with what you feel is appropriate and then begin discussions with care home staff on the first steps to taking your FIP forward.

The FIP asks you as family members to think about ideally how often you would like to be in the care home and how long the time you spend there could be. These questions as well as the other questions in the plan are not designed to pressurise care home staff – they should be used as a way for families to plan out what is important to them and be the starting point for discussions and conversations about what is possible in the immediate term, shorter term and longer term. If something you ask for is not possible at all then it is important to be ask for an explanation of why not and then suggest alternatives that can be achieved.

You should ask if a copy of your FIP can be included in the care plan of your relative and all relevant staff aware of it and the contents. You should also have a copy for your own records.

¹ <https://www.simplypsychology.org/maslow.html#gsc.tab=0>

Family Involvement Plan (FIP)

Name:		Date:	
Name of Resident:			
Relationship to Resident:			
How long have you known the resident?			
Ideally, how often would you like to be in the care home? <i>Please tick</i>			
Everyday <input type="checkbox"/>	Twice a week <input type="checkbox"/>	Once a week <input type="checkbox"/>	Once a fortnight <input type="checkbox"/>
Once a month <input type="checkbox"/>	Other:		
Ideally how many hours would you like to spend with your relative? <i>Please tick</i>			
<1 hour <input type="checkbox"/>	1 hour <input type="checkbox"/>	2 hours <input type="checkbox"/>	3 hours <input type="checkbox"/>
4 hours <input type="checkbox"/>	As long as they like <input type="checkbox"/>		
What did you do with your relative before the pandemic in the care home or at home if they moved into the care home during the pandemic?			
What would you like to continue doing now or begin doing now?			
What is important to me:			
Best ways to involve me:			

Best ways to communicate with me? Please tick	
Phone <input type="checkbox"/>	Email <input type="checkbox"/> In person <input type="checkbox"/> Facebook <input type="checkbox"/> By newsletter <input type="checkbox"/> Relatives meeting <input type="checkbox"/>
What will help create a safe space for me? <i>(E.g. Be honest, tell me even if it will be difficult for me to hear, let me cry, tell me at the beginning that there is information that will be upsetting, ask me what you can do to make it safe before we start)</i>	
Other family members/relatives who would like to be involved in the care and what they would like to do:	
Any activities or interventions connected to my relative's health I want to contribute to: <i>(For example: Speech and Language, Physio etc)</i>	
Family signature:	
Staff signature:	
Review date agreed for FIP:	

A copy of this FIP should be included in the care plan of the resident and all relevant staff aware of it and the contents. A copy should also be given to the relevant family member for their records.

Activities for families when short of time or anxious about reconnecting



As a family member of a person living in a care home, you are likely to be looking forward to being able to reconnect with them. However, you may also be feeling worried about how much they may have changed since you last saw them. If your family member has dementia you may be anxious about reconnecting with them.

You might also be concerned that they will no longer recognise you or be able to communicate in a way that you understand. Some of you may be worried how to fill the time you spend with them if it is a short timeframe. These concerns are completely understandable and many of you will be feeling some trepidation about spending time with them again.

Here are some evidence-based suggestions on activities you can use to re-engage with your loved one when you may have a limited amount of time to spend with them. The following will provide you with some ideas on how to initiate meaningful contact and connection with your loved one.

If your family member doesn't have dementia you may still find some inspiration in the suggestions below in thinking about what you may want to do together when you see each other. Some of the suggestions may not be possible straight away due to safety procedures that may be in place but they can be something to think about and plan for in the future and could be something to include in your Family Involvement Plan (FIP).



When you arrive

When you first see your loved one or enter your loved one's room start with a warm hello. You could try greeting them with a well-used catchphrase or a pet name that you are both familiar with. If you don't see any signs of recognition, please don't worry. You may look different to how the person remembers, this may be caused by having to wear unfamiliar pieces of PPE or they may now remember you as you looked when you were younger or as a child.

Your loved one may not recognise you right away or at all during the time you are with them. This is likely to be upsetting for you but rest assured that this is normal for a person living with dementia as the condition progresses. Trying not to take this personally will be difficult at first but it will help if you can remember that this isn't deliberate. To facilitate recognition, you might try wearing your regular perfume or aftershave. Sense of smell is sometimes but not always affected in dementia and the aroma may be familiar to your loved-one.

Hints and tips for reconnection activities

- Look at family photographs together

This can be a very powerful method of helping your loved-one to recontextualise your relationship. However, there are a few things you should bear in mind before you do so. Try to avoid asking your loved one who is in the photographs or correcting them if they get something wrong. If you ask any questions at all try to make sure they are closed questions that require only 'yes' or 'no' answers. This will give the person the best possible opportunity to answer and will not require them to remember names and places.

- Listen to music

Music has an extremely powerful effect on all of us and people living with dementia are no different. Memory for music is stored throughout the brain so can remain when specific parts are damaged by dementia. You might want to play a song that you used to sing together. Even if the person can no longer sing or speak, they may still be able to hum along, clap or tap their feet to the rhythm. If the person doesn't seem to know words that they used to, try to avoid urging them to try to remember. This could be upsetting for your loved one and they may simply just enjoy listening.

- Have a snack or a meal together

You could try bringing a snack with you that you know your loved-one enjoys. For example, food from the person's childhood (e.g. old-fashioned sweeties) may bring back happy memories for them and encourage a discussion about their past. This may evoke happy memories or emotions in the person regardless of whether or not they can verbalise them.

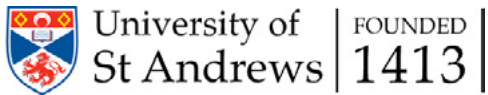
- If words have gone

If your loved-one is no longer able to speak or understand what others are saying, it is still possible to connect with them. You can use gentle touch to let the person know you are there, you may find that your loved-one wants to hold your hand. You can also try to mirror sounds, movements or facial expressions made by the person – a technique called 'Adaptive Interaction' (see link below for further information).

You are likely to have waited a very long time to see you're loved-one again in person. Try not to have any expectations about what they might or might not be able to do after all this time. Instead, try to focus on finding one activity that you can both enjoy together to start with.

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Useful Links:

What is Adaptive Interaction: <https://www.astellis.co.uk/what-is-adaptive-interaction>

Snacks: [https://www.sciencedaily.com/releases/2014/09/140922110149.htm#:~:text=The%20area%20of%20the%20brain,the%20episode\)%20is%20the%20hippocampus](https://www.sciencedaily.com/releases/2014/09/140922110149.htm#:~:text=The%20area%20of%20the%20brain,the%20episode)%20is%20the%20hippocampus)

Music helps dementia: How to harness the power of music during visits with loved ones



**Playlist
for Life**

Playlist for Life is a music and dementia charity that helps families to harness the special benefits of personal music for people living with dementia.

What is a personal playlist?

A personal playlist is simply a list of songs or pieces of music that have memories or emotions attached to them. Listening to music that is personally meaningful can help people living with dementia by calming an anxious mind, bringing cheer and making difficult tasks more manageable.

Listening to personal music together during care home visits can:

- Help families communicate and connect
- Give structure to visits, providing you with an enjoyable and meaningful activity to share that can encourage reminiscence and spark conversation or bring comfort



How to get started:

- Think of a few songs in advance of your next visit. Try to find some tunes that have memories or emotion attached. Download our **Soundtrack to your Life booklet** for some inspiration or try some of our other **free resources**. You could involve other family members and friends in this process, asking them if there are any songs that remind them of your loved one. This is a great way to involve other family members who are unable to visit.
- Play these tunes during visits. You can search for songs on your mobile phone, bring in CDs or simply sing to your loved one, whatever works best for you. Keep a note of songs that your loved one responds well to and try to delve into the memories or emotions attached. Don't worry if your loved one is unable to share their memories, as simply hearing these familiar tunes can bring comfort.
- Write the songs and memories down in a journal, notebook or on your phone to revisit later.
- You can leave a copy of the playlist in the home for carers to use when you are not there.
- By finding songs and writing down the memories or emotions attached to those tunes, you have started to build a personal playlist for your loved one.

To find out more about the benefits of personal playlist and for tips and advice on making and using playlists visit the **Get Started** section of our website for free advice and resources.

You can also join one of our **free Family & Friends webinar** on Zoom for some first-hand advice.

Creating a safe space



As a family member or relative you may feel anxious about asking questions, raising concerns or complaints or generally unsure how to begin conversations with care home staff or management. The experiences of the restrictions of lock down have created highly charged and very emotional situations which have caused some frictions in certain relationships. It is important to have some tools at your disposal to enable you to firstly create a safe space to communicate and then safe ways to question and find out what is most important to you.

What is a safe space?

A safe space is a space in which everyone feels welcome, respected and comfortable with being who they are, understanding that there is no judgement or blame. You should be able to be open, honest and speak freely.

Creating a safe space

- Listen to each other
- Allow each other a chance to speak. One person speaks at a time.
- Only share information you are comfortable sharing and this is not forced
- Respect other peoples limits and feelings, ask them if you are unsure
- Speak respectfully about people whether they are present or not
- Everyone's opinions and experiences are valued equally
- Disagree with statements, not with the people making them
- Everyone is aware of the words and language they use and how this may make others feel and the effect it may have on them
- There is no shame and blame, only safe questioning and learning

Whether you are speaking on the phone, sending an email or having a conversation face to face, you can begin by asking or writing down that you would like to create a safe space. You can let the other person know how you are feeling at that particular time e.g. anxious, sad, angry or worried. It is also helpful to set out what you need from the beginning e.g. an opportunity to ask questions, honest answers even though it may be tough to hear them etc.

It will also be helpful for you to note down any questions or queries you have beforehand to make sure that you can keep the conversation focused and cover everything you need to or require an answer on.

Many families have expressed a real fear that if they complain or "rock the boat" then this will end up having a negative impact on their relative who is living in the care home. Using language such as complaint or

complaining sets up an atmosphere for conflict or challenge. You can still ask questions about your relative and their care in a safe way which also puts the staff member at ease and should enable two way conversations which result in actions or resolutions which are beneficial for everyone.

Safe ways to question

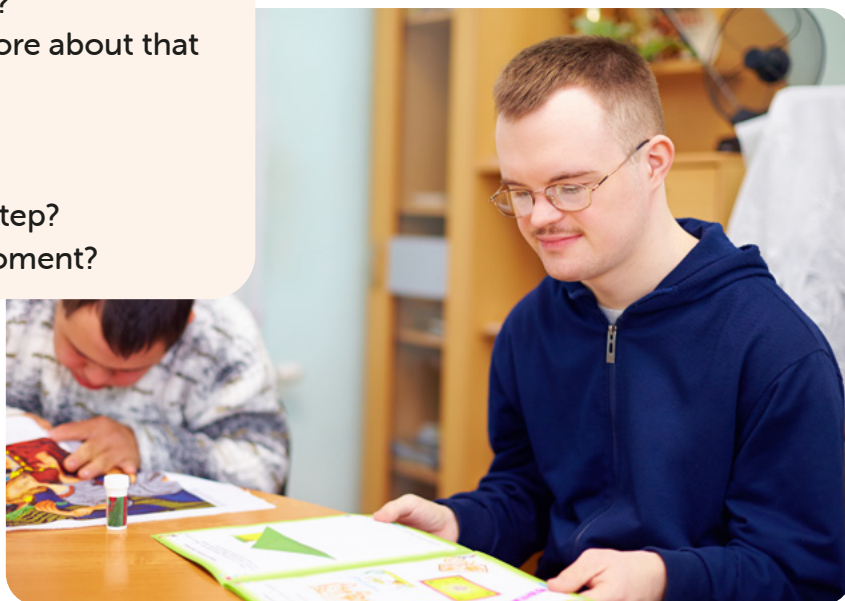
If you want to ask a question, raise a concern or find out information about your relative it is helpful to start the questions in a safe way. These questions are based on the work of social researcher, Brene Brown¹ and the Dare to Lead programme. They are a really great tool to have in conversation where you want to question effectively, keeping the conversation open and allowing you to remain focused and in control.

Staying away from language such as complaints and complaining (which often sets up an atmosphere of perceived conflict) and if you set up a safe space to begin with using some of the safe questions below it means that the person you are speaking to has to give you a fuller answer other than yes, no or I don't know and it opens up a wider conversation.

It will also hopefully lead to a better outcome where you can both have an opportunity to be open and honest with each other, even if you have struggled with this in the past.

Try using one of these:

- Can you help me understand?
- Can you tell me more about?
- Can you walk me through that?
- Tell me why that doesn't work for you
- What would work for you?
- Can you explain a little more about that decision to me?
- How can I help?
- Can I suggest something?
- What would be our next step?
- What is possible at the moment?



¹ www.daretolead.brenebrown.com

Communicating with care home staff



It's important in the restoring and reconnection of relationships with care home staff that you are able to hear from them about how the situation is affecting them. This may also help you if your relative has moved into a care home during the pandemic and you have not had an opportunity to get to know staff in a more in depth way. It is vital for any communication or conversations going forward that you both see it from each other's perspective as this can help open conversations.

Experiences of care home staff

"We have had to manage guidelines and procedures which change often and without much notice"

"We feel like relationships with families have been stripped away. There are lots of new families who we don't even know"

"We feel vulnerable, fearful and under pressure"

"We feel left out on a limb"

"Many of our roles have changed and we have lots of new activities or tasks to learn"



How care home managers feel

"No decision we make is made in isolation, decisions we make affect a lot of different people and are made with the best intention at the time"

"We feel a constant level of threat hanging over us – like we are out on a cliff edge with no support"

"We are weary and anxious and drained, I don't recognise myself anymore. We are firefighting most of the time and just trying to do what is best"

"All we wanted was to keep everyone safe and connected"

"As managers we have had to open up to a new level of vulnerability that hasn't been addressed"

"We have responsibility for the safety of staff, residents and family members and that keeps me awake at night. That is an overwhelming responsibility for people's lives as well as keeping staff motivated and on board with everything"



Going home checklist



Going home after spending time with your family member or relative will leave you with a mixture of emotions and feelings and it's important to pause and work through your feelings. Go through the checklist to help organise your thoughts and what you can do:

- Be kind to yourself – give yourself a break, this is really hard
- Take 5 minutes to think about your time spent with your loved one today
- What was difficult about today? Sit with those feelings and allow them to pass through your body – cry if you need to, feel sad/angry if you need to.
- Say how you feel out loud and finish by saying and “I am letting it go” or write down how you felt and say to yourself “I am letting it go” as you write the words
- Think about what went well – sit with those feelings and allow them to pass through your body – smile, laugh, feel happy
- Be proud of what you have with your loved one and what you do for them
- Leave your guilt at door as you leave the building – you have to continue living – it's ok that you are able to do some of the things your family member may not be able to do
- Rest and recharge when you get home
- “Pick one thing” that makes you happy and that's just for you. Write it down on a post it note and stick it somewhere you will see it everyday (on the fridge, your bedside table or the mirror) and each time you see it and read it, remind yourself you need to do something good for you to help you through each day.
- Check in with family, friends or a trusted source of support for you if you need
- Remind yourself that what you are feeling is normal, expected and ok!

Unresolved loss and grief – “Emotions without a home to go to”



Grief is an experience of reaching for someone or something familiar to find they are no longer there or it is no longer the same. It is the emotions we feel when everything that is familiar and safe to us changes. As you have experienced long periods of separation from your loved ones you will have experienced feelings of grief and bereavement but you may not have connected it in this way due to the fact the your loved one is still living, however during this time families and relatives are grieving:

- Lost time that they will never get back
- Connections and relationships
- Making memories
- Caring and loving someone
- The physical and psychological changes in people over time

This grief may be a continuation of the grief first triggered when the decision was made for your family member or relative to move into a care home. That is one of the hardest decisions for families to make and comes with a lot of guilt around whether that is the right decision or not. Many families will not have dealt with that grief as lockdown began and were then triggered into new cycles of grief which have remained unresolved.

This type of grief can last a long time and can be more severe and intense over time. It may be interfering with your ability to function normally in every day life. You may be feeling anxious, weepy, and angry or struggling to focus during the day or sleep at night. Many of these issues will be being caused by your unresolved grief.

You may be holding on tightly to the hope that if you are able to begin spending time with your loved one again, you can go back to normal or the way it was before. Such a lot has changed over the last year that you may have to prepare yourself for the possibility that this will not happen in the way you imagine or expect. The pandemic is an unprecedented event that no one was prepared for and the level of grief and pain of families could not have been predicted.

Top tips to help manage feelings of unresolved grief and loss



Feelings and behaviours of grief and bereavement are very much permitted and accepted in society when there is loss of life. The common assumption is that they only occur when there has been a death. But when you are caring for someone living in a care home during the pandemic you can experience feelings of grief and bereavement whilst the person is still alive, loss does not just mean loss of life...

It is important that you recognise in yourself that many of the feelings you have experienced during lockdown will have come from that unresolved grief and loss due to the separation from your loved one living in a care home.

You should seek support from your GP or any health professionals you currently see and tell them you are grieving and ask for help with grief.

What can help you manage these feelings of loss and grief?

- Always hold onto the fact that whatever you are feeling is ok and normal – there is no right or wrong way to grieve or feel loss
- Remember – there is no “normal” timetable for grief (take your time and do what feels right for you and no-one else)
- Don’t try and do this alone – ask for help
- Peer support is the best – connect with others who have experienced similar things to you and who understand, connect with them and talk about how you feel
- Remind yourself you are doing the best you can
- Don’t let anyone tell you what to feel (give yourself permission to feel they way you do, just because the person is still living doesn’t mean that these feelings aren’t real and aren’t painful)
- Feel the feelings – acknowledge your pain, anger and sadness (they are all part of grieving)
- Find a way to express your feelings – write, draw, take photographs or through music (whatever way works best for you)
- Think about self-care, do something for you that’s just for you that brings you some happiness to help you through the rough times
- If you have an employer – find out what bereavement support exists for staff, does it cover anticipatory grief? If not ask if this is something they would be willing to look at.



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together in dementia everyday



Acknowledgement

We would like to thank all of the families and relatives of people living in care homes and all of the care home staff and managers who gave up their time to support the development of the toolkit. We appreciate how open and honest everyone was about very complex and emotional aspects of their individual experiences.

It is important to seek support for your own health and well-being during this time. Speak to your GP if needed, talk to family, friends or go to other trusted places of support including:

The National Wellbeing Hub

Visit www.nationalwellbeinghub.scot

Call The National Wellbeing Helpline on
0800 111 4191

www.tide.uk.net
carers@tide.uk.net

@tide_carers 

@tidecarers 

