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Moving forward

**A guide for families, relatives
and friends involved in and
supporting people to move
into a care home**



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Introduction



Caring for a family member or close friend is a huge responsibility. It can be stressful and exhausting, but it can also be a huge privilege. For many people there will come a time when conversations and situations lead to a decision that the person you care for should move into a care home. For families and friends that conversation and decision is extremely difficult as it signals that a change of lifestyle is needed for the person and that moving into care would be best for them. In doing so, that decision often signals that the person can no longer cope at home – for families and carers, this opens up a huge range of practical issues and emotions.

Making this decision in no way conveys weakness, and in no sense suggests you are giving up – rather it is a strong decision as it results from an honest appreciation of the needs of the person and you as the carer. By making this decision, you are trying to create the best quality of care and lifestyle for the person in need of support.

However, none of this is easy and it in no way resolves the need for ongoing care and involvement from families – quite the opposite – families are needed more than ever to advocate and be actively involved in a partnership with the care home staff to meet the needed levels of support for the person – medically, socially, emotionally and spiritually.

A relative or friend moving into a care home may trigger lot of different thoughts and emotions. Sometimes, these thoughts can focus on negative feelings about the move but it is important to balance these with the positive aspects.

This resource aims to support you through this process. At the very heart is family, love and connection. Connection when you love and care for a person that is living apart from you is such an essential part of maintaining your relationship – 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.

This resource will support you to –

- Prepare and work your way through making the decision
- What to think about when choosing a care home
- Creating a Family Involvement Plan to begin building a partnership with care home staff
- Create and maintain safe spaces and safe conversations with care home staff
- Understand and manage the feelings connected to the grief you are experiencing as the person moves into a care home
- 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 is the fear of no longer being involved or part of their relatives care once they move into a care home and feeling detached from their care.

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. 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 complement 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 but also the potential to meet the next level of psychological needs of the residents. The FIP can provide reassurance for families and offer an opening step to establishing a transparent and equal partnership between the families and staff resulting in better outcomes for the person living in the care home.

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 asked 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 were the key things that you did with or for your relative when they lived at home?					
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? <i>Please tick</i>	
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.



Getting prepared

Here are some thoughts and ideas from families who have gone through this process which you may want to consider as you set foot on this new journey:

Practical suggestions:

Establish Power of Attorney (for both finance, health and wellbeing)

Contact Social Work to get a social worker assigned. The involvement of a skilled and empathetic social worker can be invaluable in making things happen and in accessing financial resources, listing and evaluating available care home etc.

Become familiar with the funding available to you, as this may determine the care homes that are possible

Identify suitable care homes to ensure they cover present and future needs (e.g. do they have a facility for specialised dementia care?) Ideally, you would not want to relocate the person again if they deteriorate. Power of Attorney should enable the carer to be actively involved in identifying and sourcing the most suitable care home.

If possible, speak to other people who have relatives in the care homes you choose

Have a good, honest discussion with the person to fully understand their views on their care and lifestyle for the future if possible

Consult all relevant family members who are involved in the care of the person to ensure everyone understands the position and are involved in future care

Discuss the situation with the person often, reinforcing the positives of this move

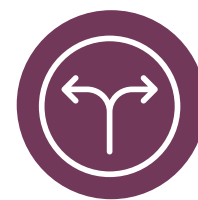
Reassure the person that you will be there to ensure the move goes well and that they will still see you once they have moved into the care home

Prepare a Family Involvement Plan and get agreement from all family members involved – then present this to the care home manager

Consider what you want the staff to know about the person. Put this in writing to be given to the care home manager and the allocated nurse and key worker in the care home – also worth giving a copy of this and your Family Involvement Plan to the Social Worker

Making the decision

It is not unusual to experience a range of emotions when you begin to make the decision about your loved one moving into a care home – these will often be triggered by guilt and fear. These may be some of the thoughts and feelings you experience:



Guilt triggers:

- The person may have made it clear throughout their life that they did not want to move into a care home and have asked you to ensure this does not happen
- You are unable to provide the care and support the person needs
- You thought you would have coped
- You feel you have failed the person and admitted defeat in trying to care for the person yourself
- The perceived, or actual, perception that the person feels you have let them down and that this may change the relationship you have with them
- You could have done more or sought different options



Fear triggers:

- The unknown of a new setting for the person and for yourself
- A loss of independence for the person and the impact this may have on them
- Whether the person will settle and be happy
- The staff not knowing the person as an individual, in the way that you do
- A decline, physically/ cognitively in the person
- What the future looks like for the person and yourself
- A loss of control in how you currently support the person
- How much, and what kind of, meaningful contact you will be able to have with the person
- How to build positive relationships with management and staff, but also how to be able to raise concerns

As a family or the person with the responsibility of making such a significant decision, it is normal to feel or experience these thoughts. You may experience all, some or none of these emotions – everyone is different, but it's important to be aware that experiencing a range of emotions is perfectly understandable. It is also important to realise that some of these emotions, and others, may occur at different stages throughout the care journey, and indeed beyond.



Visiting care homes in order to make a choice:



When visiting care homes to make a decision about which one you want to choose it can be really overwhelming trying to think of everything that you want to know or ask about. Here are some helpful hints suggested by carers who have gone through this decision process and some of the things that they felt you may want to reflect on:

Prior to any visit:

- Is a member of the management team able to meet with you?
- Are you able to have a tour of the care home?
- Visit their website if they have one

During the visit:

- How empathetic is the member of the management team to the person's possible move, but also to your own possible feelings about the move?
- Do they readily answer your questions?
- Do they seek to allay your concerns?

As you get a tour round the care home, try to view as many different areas as possible:

The Bedroom: ease of layout and personalisation

The Lounge: how is the seating arranged – are people sitting in a large circle, where interaction may be limited?

The Dining Room: are the tables nicely set? Is it laid out so that people can have a pleasurable dining experience?

Toilets: are these clearly signposted? Are they clean inside with appropriate things in place? e.g. soap, nailbrush etc.

General things to note from the tour of the care home:

- Is there a nice atmosphere/ethos?
- Is it clean and tidy?
- Are there visible trip hazards in common areas?
- Do the residents seem settled and happy?
- Are the residents engaged in activities?
- Are people's rooms easily identified with names or pictures to individualise them in order to help gain independent access?

- Is there clear signage/pictures of public areas e.g. dining room, lounge, toilets?
- Comments from other residents about how they find living in the care home

Some questions/thoughts you may wish to ask about/reflect upon:

- How personalised can the person's bedroom be?
- How is the person's money managed?
- Does a hairdresser/chiropractor visit?
- Is the person able to keep their own GP?
- Do other professionals visit? e.g. physiotherapists etc.
- How many activity coordinators are there?
- Are there a variety of activities for residents to participate in?
- Can activities be personalised to an individual's interests?
- Do arts professionals etc. come into the home? e.g. music groups, theatre groups etc.
- Is it possible to take a resident out on an excursion/outing?
- Are there outings organised by the care home – how are these funded?
- Does the care home have its own transport? e.g. minibus
- Is there flexibility of the time a person can get up and go to bed?
- Are there protected mealtimes?
- Can you help to support a person at mealtimes?
- How are special diets catered for?
- How is the person able to practise their faith?
- Is there a relatives' group?
- In what ways do staff communicate with relatives?

The move and the days and weeks after



Once your loved one or friend moves into the care home you may decide to visit straight away if you feel this will help the person to settle, or you may decide to delay a visit for the same reason. You may not be living near the person who is moving and so staying in touch on the telephone with the care home will help you to keep updated on how the move is going. When to visit is very much an individual choice and there is no right or wrong answer, you should do what is right for your loved one and what is right for you.

It may also help to ask other family members not to bombard the person with visits early on as this could get overwhelming for the person and for the care home – try to find a good balance in the beginning until everyone gets used to the new surroundings and routines.

Other things that may be helpful to think about in those first few days and weeks are:

- Make staff aware of how often you plan to be in the care home and how you want to support your loved one*
- Seek to develop good relationships with management and staff from the beginning
- Trust and communication are essential. You need to be able to establish trust as early as possible and make it known the level of communication you desire/expect
- Emphasise that you want this to be very much a shared partnership, if this is what you want
- Inform the staff what you would still like to be involved with, concerning care and support of the person, let the staff know what you did with person and the extent of your involvement before their move to the care home*
- Recognise and acknowledge that you and staff can complement each other to enable the best possible care for the person
- Let the staff know all about your relative (oral and written) – you know them best
- Be encouraging of staff when they are doing a good job – some home baking or a thoughtful card often lets people know they are appreciated
- If you have concerns, raise them quickly and seek to work together to resolve these
- Speak regularly to care home management and staff to establish how this transition is working and whether they have any ideas and suggestions. Try to reinforce that this is a team effort with everyone involved to work together for the best care possible as the future evolves

*(The Family Involvement Plan (FIP) will be very helpful here)

The future – supporting you to move forward too



Once your relative or friend is settled in their new home it is important for you to think about what you are going to do now and how you also move forward with your new normal. Here are a few suggestions of things that might be helpful to think about in the future:

- Review and, if necessary, amend the Family Involvement Plan as circumstances change – discuss this with the care home and keep the communication flowing between you
- If you are employed, speak to your manager or HR department to ensure that they are aware of your circumstances and responsibilities. You may need to visit the care home at immediate notice in the event of an emergency, so it is important that people at work understand and can support you with this
- As a carer – be very kind to yourself. Ensure you sleep well. Maintain all of your interests, social life, and activities as best you can. Arrange support for the person in care so that you can go on holiday. You cannot provide your best for the person if you are not at your best yourself
- Try to put down that heavy weight of guilt. Moving a loved one into a care home is an experience that countless others are sharing, and can be a positive choice for both the person and yourself. If decisions are made in good faith, accept this and don't wear yourself down by persistently re-visiting them
- Consider joining your local carers' group
- Consider going back to work if you have stopped working due to your caring role or look for opportunities to volunteer or take up a new hobby giving you connections and the chance to get out and meet new people

Finally, remember the opportunity and privilege caring for a loved one offers. Much of this is very difficult, but you will also create and find treasured moments. In the future, you will look back assured that that you have done the very best job you could.

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. 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

What is important to families, how can care home staff help?



It is important to us that our relative experiences a comfortable home from home, within a care home environment. This is now their home and should be viewed as such by everyone. Staff within the care home play a vital role in establishing a homely environment, as well as providing care for the person's health and wellbeing.

Knowing that our relative is being cared for compassionately, will impact our health and wellbeing in a positive way. The best possible care and effective communication can help greatly help to ease our worries and concerns. Here are some thoughts and ideas where care home staff can help family members as we travel on this journey:

- Please try to understand the myriad of emotions that family members, may experience when someone moves into full time care, and help with this transitioning process
- Make us feel welcome and valued at all times
- Take time to listen attentively and empathetically to what family members are saying
- Please try to understand that family members know the person best
- Establish the most convenient method of communication with family members and also the level of communication required
- Strive to build up trust from the outset with family members
- Find out about family members so we can chat. Sometimes, we may want to talk about things other than care
- Always be honest with family members and do not withhold important information concerning health and wellbeing – even if this is difficult to impart
- Please understand that we will still have worries and concerns about our family member, as our responsibilities do not cease when they move to a care home
- We still have an active role to play, so please involve us as much as possible
- If we have an observation or comment to make, please do not feel threatened or criticised. Rather, please understand that we are simply trying to do the very best for the person we love and care about and would ask that you work with us to resolve any issues quickly and amicably



Going home checklist for relatives and friends

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 is difficult or hard 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

Did you have a good time today? 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 on 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!

Living grief and loss



We typically associate and connect feelings of grief and loss with death and don't recognise that grief can occur when a person is still living. 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. Making the decision about a loved one moving into a care home will trigger feelings and emotions of grief – they may come from a combination of things and you may ask yourself some of these questions when processing the decision that your loved one is moving into a care home;

Loss of Attachment	Who am I connected to?
Loss of Territory	Where do I belong?
Loss of Structure	What is my role?
Loss of Identity	Who am I?
Loss of Future	Where am I going?
Loss of Meaning	What is the point?
Loss of Control	I feel overwhelmed

This type of grief can last a long time and can be more severe and intense over time. It will feel like a roller coaster and you will have good days and bad days throughout the time that your loved one is living in a care home. If you don't allow yourself to recognise and acknowledge that you are grieving then your grief remains unresolved and it will eventually begin affecting your every day life. You will start to feel it physically and emotionally and struggle to know where it is coming from and why.

You may be feeling anxious, weepy, and angry or struggling to focus during the day or sleep at night. It is vital that you recognise these feelings, allow yourself to feel them and seek help and support for grief.

It's important to find ways that work for you to manage your feelings of grief and be aware of potential triggers and some processes you can put in place to help.

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 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 will have come from that unresolved grief and loss due to your relative or loved one moving into a care home.

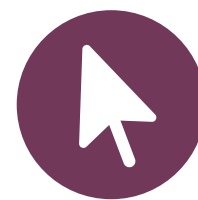
You should seek support from your GP or any health professionals you currently see and tell them you are grieving and ask for help with grief.

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.

Useful links

Here are some useful links to websites that may be helpful as you work through this process and make decisions;



- <https://www.alzscot.org/>
- <https://www.careinspectorate.com/>
- <https://www.tide.uk.net/>
- <https://www.ageuk.org.uk/scotland/>
- <http://www.solicitorsforolderpeoplescotland.co.uk/>
- <https://www.mygov.scot/care-homes>
- <https://www.gov.scot/publications/health-social-care-standards-support-life/>
- <https://www.mygov.scot/power-of-attorney>
- <https://www.citizensadvice.org.uk/scotland/>
- <https://www.mwcscot.org.uk/>
- <https://pamis.org.uk/>





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together in dementia everyday



Acknowledgement

We would like to thank the family members and relatives who were involved in creating this resource. 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 