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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 privilege which can also be stressful and exhausting.

A time may come, when the person you care for, requires added support that cannot be met under their current living environment. This leads to family and friends discussing moving the cared for person forward to a residential care home setting.

This can be a difficult conversation and reaching a decision is extremely difficult, even when the move is best for the cared for person. It signals a change for everyone, especially for the person that will be moving into a new home. This move will have a transitional settling in period.

Making this decision may trigger deep emotional feelings for family and friends. This is normal. It does not convey weakness, you are not giving up – it is a strong decision that is born from love, an honest appreciation of the needs, and best outcomes, for everyone. By making this decision, you are aiming to create the best quality of care support for the person in need.

Making these decisions is not easy and in no way resolves the need for ongoing care and involvement from families. Quite the opposite, families are needed more than ever to advocate, to be actively involved in a collaborative partnership with the care home staff to meet the required levels of support for the person, including 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. It is important to balance these with all the positive aspects.

This resource aims to support you through this process. At the very heart of this are family, love, and connection. Maintaining a relationship with the person that you love and care for is essential. Connection and love are what families hold on to, nourish, and protect for as long as they can, 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”



Families reported that their biggest fear is to be excluded from their relative’s care following the transition of their loved ones into a care home.

They fear being detached from a loved one.

Below are some thoughts families 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 “shared care”. Relatives have value in their caring responsibilities. Families may wish or may not wish to continue contributing to their relative’s care and it is vital to respect and enable choices. The FIP enables families to share and document the care and activities they participated in with the person living in the community and to express what they would like to continue with.

We created a Family Involvement Plan (FIP). The FIP will enable families to illustrate the love, connection, and shared care with a relative before the transition into a care home setting. The FIP will complement the care and activity plans that already exist within a care home, and, is designed to be flexible and adaptable as a person’s needs, outcomes and conditions evolve. This tool enhances the care of a person and supports the care and activities already in place by the provider.

The FIP is a positive aid for all parties involved in a person’s care, and, its use is to achieve the best outcomes for a resident. It is not a complaint tool. The sole aim is to enhance the care already planned and assist care home staff to develop care plans and activities for residents.

The key to the FIP is that it will aid person-centred care in the truest sense of the word. It is underpinned by love and connection between families. 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 family members to think about how often they would like to be in the care home and what length of time they may spend there. These questions, as well as the others in the plan, are not designed to pressurise relatives or staff. Instead they should be used as an aid for families to plan what is important to them. The FIP is a starting point for discussions around what is achievable in the immediate, shorter, and longer-term. A relative may ask for something that is not possible, if this occurs, ask for an explanation and suggest achievable alternatives.

A copy of the FIP should be included in the care plan of each 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

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>	
<div style="border: 1px solid black; height: 150px;"></div>	
Other family members/relatives who would like to be involved in the care and what they would like to do:	
<div style="border: 1px solid black; height: 150px;"></div>	
Any activities or interventions connected to my relative's health I want to contribute to: <i>(For example: Speech and Language, Physio etc)</i>	
<div style="border: 1px solid black; height: 150px;"></div>	
Family signature:	<div style="border: 1px solid black; height: 40px;"></div>
Staff signature:	<div style="border: 1px solid black; height: 40px;"></div>
Review date agreed for FIP:	<div style="border: 1px solid black; width: 400px; height: 20px;"></div>

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

Below are some hints and tips that families may wish to consider when a loved one is moving into residential care

Practical suggestions:

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

Contact Social Services to get a social worker assigned. The involvement of a skilled and empathetic social worker can be invaluable. They are knowledgeable and can assist in many areas. They can speed up the processes; have access to financial resources, have named care home lists in your area along with relevant evaluation reports.

Explore if any funding is available, this may assist with the choice of care homes within budget.

List care homes that can continue care should a resident's condition deteriorate. (e.g. do they have a facility for specialised dementia care?) This information may prevent a relocate. Power of Attorney will assist in making choices.

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 present and future care of the person.

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

If possible, discuss the move with the person moving often, to reinforce the positives.

Prepare a Family Involvement Plan for all relevant family members then pass it to the care home manager on completion.

Consider what you want the staff to know about your relative. Write it down, and give it to the care home manager, the allocated nurse and a key worker in the care home. Share copies of these with the Social Worker also.

Making the decision

It is normal to feel a range of emotions when making the decision to move a loved one into a care home. They can be positive or negative feelings. Some of these emotions can be triggered by guilt or fear. Below are some of the thoughts and feelings you might experience;



Guilt triggers:

- The cared-for person may have made it clear throughout their life that they did not want to move into a care home, they may have asked you to ensure this did not happen
- A promise may have been made to carry out a loved one's wish, however, for many reasons, these wishes cannot be fulfilled.
- There may be feelings of personal failure, e.g. what more could have been done to prevent this move?
- Making this decision may induce feelings of worry about relationships, e.g. Have all other options been explored?



Fear triggers:

- Fear of an unknown setting may for both the family and cared-for person.
- Fear of an impact on the cared-for person's happiness, will they settle?
- Fear of care home staff not knowing the cared-for person's individuality in the same way that family and friends do.
- Fear that a loved one may decline either physically or cognitively following the move.
- Fear of what the future may look like for both the cared-for person and the family.
- Fear that family may not be able to continue with support for the person moving.
- Fear of how much meaningful contact will continue following the move.
- Fear of how to build positive relationships with management and staff.
- Fear about raising any possible concerns that may arise.

It is normal to experience these feelings and thoughts when making such a significant decision. A family member can experience all, or, none of these emotions. These thoughts and emotions can arise at any point, e.g. prior to the move, during the move, or post the move.

It is important to know that the move may have positive feelings and emotions too, these positive feelings and emotions are normal. It is also important to realise that these emotions, positivity, fear, or guilt, can occur at different stages throughout the care journey and beyond.



Visiting care homes in order to make a choice:



It can be overwhelming choosing the most suitable care home that supports a loved one's needs and outcomes best. There is a lot to think about! Below are some helpful hints and tips suggested by carers who have already gone through the decision process.

Before any visit:

- Ask for a member of the management team to meet with you
- Request a tour of the premises
- Visit their website if they have one
- Write a list of questions you wish to ask

During the visit:

- How empathetic is the member of the management team regarding the feelings of all in the potential move?
- Are any questions readily answered?
- Have any concerns been alleviated?

View as many areas of the care home as possible. Below are some of the areas and questions to consider when making a choice:

The Bedroom: Does this area have ease of layout with space for personalisation?

The Lounge: How is the seating arranged? Are people sitting in a large circle where interaction may be limited? Noise Level, is the television blaring?

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

Toilets: Are toilets clearly signposted? Are they clean and do they have the relevant and accessible toiletries?

General things to consider when visiting a care home:

- Is there a nice atmosphere?
- Is the home 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 rooms easily identifiable with names or pictures to keep individuality and independent access ?

- Are there clear signage/pictures of public areas e.g. dining room, lounge, and 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:

- Is it possible to personalise bedrooms?
- How are residents' finances managed?
- Does a hairdresser/chiropractor visit?
- Are residents able to keep their GP?
- Do other professionals visit? e.g. physiotherapists
- 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 entertain within the home? e.g. music groups and theatre groups.
- 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 time for a resident to get up in the morning or go to bed in the evening?
- Are mealtimes protected?
- Can a resident be supported by family at mealtimes?
- Are special diets catered for?
- Are residents' supported to practice their faith?
- Is there a relatives' group?
- What methods are used for staff and relative communication?

The move and the days and weeks after



A choice has been made and a loved one has now moved into residential care. The decision to visit straight away, or, not to visit straight away, is personal. There is no right or wrong way. Visiting immediately can help a loved one to settle into their new home, equally, it may be best for them to have some personal space to adjust to their new surroundings.

The practicalities of visiting a loved one right away can be difficult for many reasons, e.g. distance, work or family commitments. Communicating with staff via the telephone or email will keep you informed on how a loved one is settling into their new home.

It may help if family members restrict visiting early on to reduce any overwhelming feelings for both a new resident and care home staff. Try to find a good balance in the beginning until everyone gets used to new surroundings and routines

The below tips may be useful to think about in those first few days and weeks:

- Make staff aware of how often you plan to be in the care home and how you want to support your loved one*
- Develop good relationships with management and staff from the beginning.
- Communication and trust are vital for good relationships. Advise the management and staff of the level of communication expected.
- If it is your wish to have a shared partnership, emphasise this, share with the staff how important it is.
- Inform the staff of any wish to remain involved in a loved one's care and support. Let the staff know what level of involvement you had before the move into the residential care home *
- Recognise and acknowledge that families and staff can complement each other as a team to enable the best possible care for the person.
- Inform staff of a loved one's history, hobbies career where they were born. This is very useful information.
- Recognising that staff is doing a great job, and that their work is appreciated and valued, is a good way of building relationships. Saying thanks can be done in so many ways and with so many gestures.
- Raise any concerns quickly and seek to resolve them together, work in partnership.
- Speak regularly with care home management and staff to establish how the transition is working. If there are any issues, work together as a team on ideas and suggestions to reach the best possible resolutions. The best care outcomes will be reached via a team effort.

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

The future - supporting you to move forward



Once a relative or friend is settled in their new home, a carer needs to think about how they move forward with a new normal. Below are a few suggestions that might be useful for their future;

- Review or amend the Family Involvement Plan as or when circumstances arise – discuss this with the care home and keep the communication open and up to date.
- 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 attend the care home, immediately in the event of an emergency. Keeping management informed is important so that your employer can support and understand you when necessary.
- Be kind to yourself. To help achieve this, try to sleep well, maintain all of your interests, social life, and activities if possible. Arrange additional support for the person in care so that you can take a holiday. You cannot provide the care best for a person if you are not at your best self.
- Try to lay down the heavyweight of guilt. Moving a loved one into a care home can be a positive experience for both the cared-for person, and the carer. It is an experience shared by many. Decisions are made in good faith, accept this and don't wear yourself down by persistently re-visiting prior concerns.
- Consider joining a local carers' group.
- Consider returning to work if you had stopped due to your caring role.
- Look for other opportunities, like volunteering or taking up a new hobby creating new connections with new friends.

Finally, remember caring for a loved one can very difficult, but, when can reflect, you may find caring created many treasured moments. Hopefully, you will be able to look back with pride knowing that you did the very best you could.

Creating a safe space



A family member or relative may feel anxious and unsure about asking questions, raising concerns or complaints 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 ask important questions.

What is a safe space?

A safe space is one where everyone feels welcome, respected, and comfortable. It is a space where there is understanding, without judgement or blame. A space where you can be yourself, be open, be honest, and speak freely;

Creating a safe space

- Let everyone know that it is important to listen to others.
- Allow everyone to have a chance to speak, where one person speaks at a time.
- Only share information you are comfortable sharing, information should never be forced.
- Respect other people's limits and feelings.
- Speak respectfully about people at all times.
- Make it clear that all opinions and experiences are equally valued.
- It is ok to disagree with statements, but not with the people making them.
- Be mindful of words and language and how this may impact feelings.
- The above should create a safe space for questions and learning.

If email, telephone, or face-to-face communication requires a safe space, it is advisable to make this request at the beginning of the conversation. Share how you are feeling with the person you are speaking with. Staff will understand feelings of anxiety, sadness worry, or anger. It is also helpful to set out what you need from the beginning of the conversation e.g. an opportunity to ask questions with honest answers, even though it may be tough to hear them.

It will also be helpful to note down any questions or queries before a conversation begins as this will keep the conversation focused.

Safe ways to question

Many families have expressed a real fear of “rocking the boat” by raising a concern or a complaint. There is a genuine worry that raising issues will end up having a negative impact on a relative living in the care home. The use of language is important to avoid possible conflict. Questions can be asked about a relative and their related care safely so that both parties feel at ease. This should enable two-way conversations with results, actions, or resolutions that are beneficial for everyone.

It will also hopefully lead to a better outcome where all parties have an opportunity to be open and honest with each other, even when there have been past conflicts.

Try using one of these open questions;

Try using one of these open questions;

- Can you help me understand?
- Can you tell me more about it?
- Can you walk me through that?
- Tell me why that doesn't work for you?
- What would work for you?
- Can you explain to me a little more about that decision?
- 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 an environment that is homely as well as providing care for a resident's health and wellbeing.

Knowing that our relative is being cared for compassionately, will positively impact our health and wellbeing. 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 through this journey;

- To help and support the transition of a loved one moving into full-time care, try to understand the myriad of emotions that family members may be experiencing.
- Greet families with warmth; this creates a feeling of being valued.
- Take time to listen attentively and empathetically to what family members are saying.
- Family members know their loved ones best. Ask them about the new resident so that you can get to know their history, this builds a picture of who they are, their likes and dislikes, interests and hobbies. Shared knowledge creates general chat.
- Establish a convenient method and the level of communication the family require.
- Build up a trust relationship with family members from the outset.
- Share information concerning health and wellbeing regarding a loved one with the family, even if this is difficult to impart.
- Understand that families feel responsible for their loved one and may continue to have worries and concerns after they have moved into residential care.
- Invite family to be actively involved as much as possible, this is a great way to build relationships.
- Recognise that an observation or comment is not always a criticism. Having an open conversation will resolve any potential issues quickly and amicably. Comments and observations can be useful suggestions and if used in a positive manner, can be incorporated into any process improvement plan within the work place.

Going home checklist for relatives and friends

Going home, after spending time with a family member or relative living in residential care, may leave you with a mixture of emotions, thoughts and feelings. It is important to pause and reflect on these feelings. Go through the below checklist to help process your thoughts and feelings;

- Be kind to yourself - give yourself a break, this is difficult sometimes.
- Think about the time spent with a loved one today.
- What is difficult for you or what is making you happy today? Sit with those feelings and allow them to pass through your body – cry if you need to, feel sad or angry if you need to.
- Say how you feel out loud and finish by saying “I am letting the negative feelings go”. Write down how you feel and say to yourself “I am letting the negative feelings go”.
- Did you have a good time today? What went well? Sit with those feelings and allow them to pass through your body, it is ok to smile, laugh, and feel happy.
- Be proud of the relationship and all the support shared with a loved one.
- Try to leave any guilty feelings behind. It is ok to continue to live and to do the things that you may have previously enjoyed together.
- Rest and recharge when you get home.
- “Pick one thing” that makes you happy and is just for you. Write it down on a post-it note and stick it somewhere you will see it every day, (on the fridge, on your bedside table, or a mirror), each time you see it, read it and remind yourself to do something good to take care of you.
- 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.

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 emotions and feelings 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 may feel like a roller coaster and you could have good days and bad days throughout the time that your loved one is living in a care home. Allow yourself to recognise and acknowledge that you are grieving, or your grief will remain unresolved and will eventually affect your everyday life. You may start to feel the grief both physically and emotionally and struggle to know where it is coming from and why.

You may become anxious, weepy, or angry and struggle to focus during the day. All of this can lead to poor 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 to manage the feelings of grief that work best for you. Become aware of potential triggers and put in some process to support them.

Top tips to help manage feelings of unresolved grief and loss



Feelings of grief and bereavement are permitted and accepted in society when there is a loss of life. The common perception is that these feelings only occur when there has been a death. However, a loss does not only mean a loss of life. When someone is caring for a person living in a care home, they can experience these complex feelings.

It is important that unresolved grief is recognised, validated, accepted, and can be felt when a loved one moves from care at home into a residential care home setting.

Seek support from a GP or any health professional you currently see, tell them you are grieving, and ask for support 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 a loss.
- Remember – there is no “normal” timetable for grief, take your time and do what feels right for you.
- Ask for help if you need to, don't try to cope on your own.
- Peer support is often the best to talk about how you feel. Connect with others who have similar experience and who will understand.
- Remind yourself you are doing the best you can.
- Don't let anyone tell you what to feel. You can grieve a loved one that is still with us.
- Feel the feelings and acknowledge your pain, anger, and sadness, it is normal.
- Find a way to express your feelings – write, draw, take photographs or listen to music, whatever works best for you.
- Think about self-care, take part in an activity that is just for you that will support you through the day.
- If you have an employer, find out what bereavement support exists for staff and if it covers anticipatory grief, or 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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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 has been about the very complex and emotional aspects of their individual experiences.

It is important to seek support for your 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

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