

This document is a compilation of extracts from the 'Caring for YOU!' series of magazines for caregivers. Our thanks to AbbVie for permission to share this content.

Making a contingency plan

How to plan for the future to safeguard your love one's care.

Everyone who cares for someone likes to think they will always be there for their loved one. At some point in the future, however, the day may come when you simply can't be.

The change in circumstances could be temporary – for instance, if you have an accident and need some time to get back on your feet – or it could be permanent if you reach a point when it all becomes too much for you.

Either way, it's a good idea to have a contingency plan in place to ensure your loved one continues to receive excellent care with minimal disruption.

“Asking for regular help from friends and family means they will ‘learn the ropes’ and be better informed about what's required should you need help in the future.”

Letting others in

Sharing the care burden now by allowing others to help you out not only gives you the chance to have a regular break, but it also means there are others ‘trained’ to help out if necessary.

You might be surprised how much you do that others are completely unaware of. So asking for regular help for friends and family to ‘learn the ropes’ means they will be better informed about what's required should you need help in the future (for example, if you fall suddenly ill).

Facing the future

Longer-term planning may require facing a few harsh realities. Firstly, the realisation that one day you may no longer be able to cope, and that you will have to pass your caring duties onto someone else.

This may result in all sorts of conflicting emotions, such as:

- Guilt that you have to consider a nursing home
- Feelings of failure
- Relief that you may get your life back
- Concern about what people will think
- Worry about what your loved one would say
- Worry about the cost.

It may also lead to practical questions, such as:³

- When will you know the time is right?
- What options are there for fulltime care?
- How do you arrange it?
- How will you pay for it?

However this process doesn't have to be rushed if you face two facts now:

1. Parkinson's is a degenerative disease that will eventually get worse⁴
2. It may one day be best for your loved one – and for you – to look at care options outside the home.

You can then start planning ahead so you're ready when 'one day' arrives.

Doing your research

Before writing your contingency plan, you'll need to do your research.

- What would your loved one want? If it's not too late, talk it over.
- What do you want (key benchmarks for care: quality of care, distance from your home for visiting, affordability, etc)?
- What considerations do members of your healthcare team recommend?

Writing your contingency plan

Having a backup plan that covers all eventualities might prove difficult, but you could divide it into a series of 'what-ifs'.

For example:

Contingency plan	Options	Notes
What if I need time out (irregular breaks)?	<ol style="list-style-type: none"> 1. Our friend Lorna is happy to help out occasionally and she knows Mark and his basic needs well enough to care for him for up to a day at a time. She is my No.1 backup for day breaks. Other people who have also offered support are ... 2. Our daughter Elizabeth is able to help out for periods of up to a week but she needs advance notice to arrange time off work. 3. The day care centre can welcome Mark for periods of up to ... for a cost of ... Their details are ... 	I have prepared a checklist of things Lorna and Liz need to know (routines, medications, emergency contact numbers for healthcare team, further advice, etc). This is kept in my top filing cabinet drawer, where Mark's medical records are also kept. I'm also talking to other

		<p>carers via my local Parkinson's group to work out some more ideas and options.</p>
<p>What if I fall ill and am unable to care for Mark in the short-term?</p>	<ol style="list-style-type: none"> 1. As above for short periods of time (short illnesses; broken bones etc). Elizabeth can help for longer than a week in a temporary emergency. 2. If I am unable to continue caring longer term then see next page. 	<p>I have prepared a checklist of important things (routines, medications, emergency contact numbers for healthcare team, further advice, etc.) This is kept in my top filing cabinet drawer, where Mark's medical records are kept. If I am unable to, Elizabeth has agreed to make any necessary arrangements with support from Lorna. She also has a legal document authorising her to act on my behalf if I am unable to make the necessary care arrangements for Mark.</p> <p>I've also spoken to our Parkinson's nurse and our GP about the future, so they are able to offer further advice and support if we need it at short notice.</p> <p>The contacts for the local community services office are also in the file and they may be able to help offer further advice if and when we need it.</p>
<p>What if I suddenly fall ill and can no longer care for Mark full time at home?</p>	<ol style="list-style-type: none"> 1. If emergency care is needed (e.g. if I have a serious illness and we need immediate short-term care), the day care centre may be able to help arrange temporary help for Elizabeth. 2. For full-time care options, we have visited a number of homes and our preference is for [NAME OF HOME]. They will need to be contacted to confirm availability etc. 	<p>I have prepared a checklist of important things (routines, medications, emergency contact numbers for healthcare team, further advice, etc.). This is kept in my top filing cabinet drawer, where Mark's medical records are kept. If I am unable to, Elizabeth has agreed to make any necessary arrangements with support from Lorna. She also has a legal document authorising her to act on my behalf if I am unable to make the necessary care arrangements for Mark.</p>

		<p>Costings for long-term care at [NAME OF HOME] and at our second and third preference homes are in the filing cabinet. I review these regularly. I have written a budget and a full list of our financial situation and how care costs can be covered, and this is in the file.</p> <p>I've also spoken to our Parkinson's nurse and our GP about the future, so they are able to offer further advice and support if we need it at short notice.</p> <p>The contacts for the local community services office are also in the file and they may be able to help offer further advice if and when we need it.</p>
<p>What if, over time, I reach a point where I can no longer cope?</p>	<p>I discussed this with our healthcare team and we have looked at long-term care options. We have visited a number of homes and our preference is for [NAME OF HOME]. I have agreed with Dr ... that we will keep monitoring how I cope and we will start making these arrangements when we see signs that I am struggling.</p>	<p>I've worked with a financial planner who another carer at my local Parkinson's support group recommended and we've done some costings for long-term care at [NAME OF HOME] and at our second and third preference homes, details are in the filing cabinet. I will review these regularly. [NAME OF HOME] is aware of our situation, though there is a X-month waiting list, which is something we need to keep in mind. I have also written a budget and a full list of our financial situation and this is all in that file.</p> <p>I've also spoken to our Parkinson's nurse and our GP about the future, so they are able to offer further advice and support if we need it at short notice.</p> <p>The contacts for the local community services office are also in the file and they may be able to help offer further advice if and when we need it.</p>

As with most things related to caring, it's best to be organised and cover all the 'basics' so someone else can step in if there's an emergency. Having a plan in place may also prevent you subconsciously worrying about this.

Make sure you share your plans and discuss them with your loved one if they are still able to understand and contribute. Also, run through your plans with your family and

close friends, as well as key members of your healthcare team, so they can all work together to make sure your loved one receives the best of care.

References:

- 3 L. Transtrom Narum, N., 'Caregiver Stress & Coping: The Journey through Caregiving', ed. by North Dakota Family Caregiver Project (North Dakota State University, 2003).
- 4 European Parkinson's Disease Association/AbbVie, 'Advanced Parkinson's Pathfinder', (2013).