

Tips for caring from a distance

If you live in another city, town, island or even overseas from someone with advanced Parkinson's, here are some ideas to bridge the distance.

Caring at a distance can be challenging. There is physical distance between you and the person who needs your support, and there is also the upsetting feeling of not being there, and worrying if someone you care about is reliant on the support of others.

The good news is that families, carers and friends can all absolutely still make a valuable contribution despite the barrier of distance. Here are a few tips that you may find useful.

BE PREPARED

You're well advised to build a network or at least join an existing network of the person's friends and family who keep each other up with what's happening with the person you care for.

You should develop a plan for staying in touch, providing support through other people, obtaining regular reports on the person's welfare, resolving crises and making visits when you can. It's useful if you talk to other long-distance carers (if possible) and develop knowledge of Parkinson's that you can use when talking to family or friends who may live closer.

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STAY IN TOUCH

Let your loved one know you care and you've been thinking of them. Consider sending postcards, photos, short letters, small gifts or flowers. Remember birthdays, anniversaries and the like. It's recommended you establish a phone routine so that you call at around the same time of the day. Make phone calls short. You may consider using Skype or a similar communication tool.

When you talk, like with any friend, it's good to strike a balance between updating people on what you've been doing and asking them what they have been up to and have planned for the near future.

Always tell your loved one about any actions that you are taking and be aware they might sometimes feel as if you are meddling. Have a plan for dealing with crises. Have a list by your phone of whom to contact about what issues.

Visit when you can and try to arrange your visits to give local family members some respite from caring, and keep in touch through regular phone calls or email. Be sensitive to family members who are caring on a daily basis especially if you disagree about your loved one's needs. If you are travelling long distances and can only visit on occasions, allow time for you to meet with service providers after your visit. Ask for feedback and provide them with your observations.

BUILD A CARING SUPPORT NETWORK

Arrange support via family, friends or support groups. Try to establish a good relationship with a family member or friend who lives nearby.

It's vital you have relationships with family members, friends and carers in common in case any emergency happens. It's preferable you do not contact them for the first time when there is a problem. Make yourself known. You can ask the person you care for about whom you can contact.

Try to arrange family meetings to sort out roles and responsibilities. It's very helpful to agree on criteria that may trigger the need to get together to discuss major decisions if circumstances change.

You may want to work on resolving any conflicts in the relationship you have with your other family members so that you can work together as your loved one would want you to, for their welfare.

If your Parkinson's person lives in residential care or similar, it pays to develop a good relationship with the staff so that they will know what to keep you informed about and how regularly.

If you are worried about any person that may have been hired or provided to help, say, your mother or father, make sure their credentials have been checked and don't feel shy about following up on anything that your parent says that concerns you. It's usually best to talk.

PLAN AHEAD

Try to anticipate what care strategies may be required to prevent a crisis and identify a person you can trust to accurately assess a situation and provide you with advice. Compile a list of help that's available in the area and consider redirecting mail to someone who will be responsible for the person's finances. Setting up legal, financial and medical arrangements may require a Power of Attorney.

Get consent to talk to the person's doctor rather than trying to second guess what is going on from a distance.

LOOK AFTER YOURSELF

If you are caring at a distance this can be psychologically challenging. It may be that you want to talk to someone about this, just to offload maybe. You may have your own feelings of privacy and loyalty to deal with, and possibly even denial. For example, you may not want to acknowledge that your loved one needs so much assistance, or you may feel guilty talking behind their back. Or you're just worried or tired. Be reasonable with yourself. We all need to recognise these emotions if the wellbeing and health of a loved one is at stake. What you hear or find out needs to be passed on if it can help ensure better support for your loved one.

Whatever happens, know that you make a difference.