



Gathering Support

A quick guide

Planning for your own care or for the care of someone close to you is not always easy and it can feel overwhelming. We hope this guide will help you think about the support you have around you.

*because
you matter*

St Nicholas
Hospice Care

A Registered Charity No. 287773



LA TROBE
UNIVERSITY

**HEALTHY
END OF
LIFE
PROJECT**



Starting at the beginning: Identifying your support needs

This guide, which is by no means definitive, will take you through three of the steps you can take, when building your networks of support.

This is your guide, and it is up to you how you use it. The first step is intended to get you thinking about different aspects of your everyday life. You can include as much, or as little detail in this section as you would like.

Remember you don't have to fill everything in at once and tick every box. This is your guide so there is space for you to add anything that's important to you.

The more practical stuff:

When you are ill or caring for someone the world doesn't stop, and all the little – but important – household tasks still need doing.

Food shopping	Looking after pets	
Preparing meals	Keeping on top of your to-do list	
Gardening		
Errands you need to run		

Notes:

Keeping in touch:

Feeling involved in what's going on in the lives of your family and friends can offer a lot of comfort and reassurance. It could also make opening up to them a little easier, whether that's about how you are coping with your illness or how you feel about caring for someone.

Regular calls to family	Catch-up with your neighbours	
Regular calls to friends		
Keep up with social media		
Have dates in the diary		

Notes:

The personal stuff:

Personal appointments	Medical appointments	
Work commitments		
Child care commitments		
Looking after yourself		

Notes:

Doing what you enjoy:

Making time to do the things you like is important. Time for you whether you are ill or caring is necessary.

Going to the cinema	Seeing friends	
Exercise classes	Trips away	
Visiting family	Going out for food	
Hobbies		

Notes:



Starting conversations isn't always easy.

This guide has probably already included some things you would have rather not had to think about.

This next section is intended to give you the chance to think about some of the things that are especially important to you.

Your illness might have prompted you to start looking at things differently. You might have some set ideas about what you want and don't want as well as the things you like. Here you can note down what's important to you. You don't have to share this with anyone if you don't want to, but it could be a good conversation starter.

If you are supporting someone through their illness, you can also use this next section to start conversations about their wishes.

I would like to:

See:

(people, places, familiar things, films, theatre, pets
and people going through a similar experience to me)

Feel:

(warm, comfortable, clean, touch from loved ones,
massage, home comforts, in control, pets)

Taste:

(favourite foods, tastes, drinks)

Smell:

(perfume, essential oils, cooking,
baking, fresh air, the seaside)

I would like to:

Hear:

(music, conversations, laughing, children playing, silence, background noise)



Your thoughts:

Please use this space to write down anything you think may have been missed. You could include things you may want to share with others later or perhaps things that have already happened which you would like to share. If you would rather not use this space, or don't feel able to do so at this moment, you don't have to.

Who have you got around you?

If you are ill or caring for someone we hope the second step in this tool will help you see how much support you have around you.

You can use this space to highlight all of the people in your life that may be able to offer help and support. This list will probably start with your family and friends, but it might also include your neighbours, work colleagues, GP, nurses, support groups etc.

Don't be afraid to write someone down, putting their name in doesn't necessarily mean you will need to call on them immediately or frequently, but knowing that they are there may give you some comfort.

You can also share this information with people to help them understand the sort of support you may need from them.

Everyone on the list will have a different role. You don't need to fit each person into a certain role, it might be useful to think about the sort of support each person could offer.

You might not feel ready to think about who will support you with the more private aspects of your care and support. A way to measure how comfortable you feel with each person might be to ask yourself:

“Would I feel comfortable if this person saw me in my pyjamas?”

Draw or list the people you think maybe able to support you. It might help to put yourself at the centre and work from there.



Making a plan

We all know that when you make a plan some of it can quite often go out of the window. However, the action of making a plan allows you to be in control.

It can show you any areas where further support may be needed and it can be a way for you to express your wishes to others.

The aim of this step is to look at how what you have written in step one and how that fits in with the people you have listed in steps two. You might not feel able to do this right away, or all at the same time. That's okay, it can be a work in progress for as long as you like.

This plan will change; if things aren't working the way you thought they would don't be afraid to adapt it.

It might be that as you pull everything together you find that there are areas where you need extra support. By knowing this now, you have already taken the first step to getting that additional support.

Everyone puts plans together differently, but the pointers below might be a good starting point. There's also a planning template you can use.

- Write down your weekly or monthly schedule recording when you think you might need assistance with particular tasks
- Look at the people you have identified as being able to help and see if you can match up tasks
- Start to look at any further help you might need. This could mean researching support groups, or could perhaps focus on allowing you to do more of the things you enjoy. Sports clubs, hobbies or social clubs.

Useful notes

Day	Activity(s)
Monday	
Tuesday	
Wednesday	
Thursday	
Friday	
Saturday	
Sunday	
Monthly jobs	
One off jobs	

Who/Contacts	Frequency

Useful apps

People have told us that these web based applications have been useful, however, they are not owned by St Nicholas Hospice Care and should be used with discretion.

Jointly

jointly

The Jointly app allows you to set up a 'circle of care' where you can organise the communication and coordination between those who share the care. The app includes facilities to record medications, appointments, tasks and contacts all designed to reduce the stress often felt when arranging care by family members and friends.

www.carersuk.org/search/jointly-app

CareZare

 **carezare**
HELPING PEOPLE HELP

At CareZare, we are on a mission to empower family caregivers, allowing them to provide the best possible care for their loved ones while also taking care of themselves. The purpose of CareZare is to shift care giving from a solo burden to a team-driven approach involving other family and friends, professional caregivers and outside services. Care giving can be overwhelming; CareZare is here to guide you through.

www.carezare.com/our-story

Lotsahelpinghands



Lotsa Helping Hands
CREATE COMMUNITY

With the Help Calendar, you can post requests for support - things like meals for the family, rides to medical appointments, or just stopping by to visit.

Members of your community can quickly find ways to help, and Lotsa will send reminders and help coordinate logistics automatically so nothing falls through the cracks.

www.lotsahelpinghands.com

Caring Bridge



CaringBridge is the first non-profit social network with global reach whose mission is to connect loved ones during a health journey through personal, private websites. CaringBridge allows patients, caregivers, families, and friends to exchange information about a patient's medical condition on an ongoing basis. The websites are designed to become conduits between patients, their families, friends, neighbours, and colleagues.

www.caringbridge.org

Caring Village



Caring Village is an easy-to-use dashboard and mobile app designed specifically for family caregivers, like you, making it easier, safer, and less stressful to care for an aging loved one. Your personalized village becomes the "Command Centre" for all of your care giving activities. Invite family, friends, neighbours, and care professionals to share in the care.

www.caringvillage.com

Get in touch

If you have any further questions about St Nicholas Hospice Care, please get in touch:

01284 766133

enquiries@stnh.org.uk

www.stnicholashospice.org.uk



We offer a **24 hour telephone advice line**

01284 766133

for all patients and family members as well as health-care professionals including general practitioners, district nurses and carers.

Further reading

As well as the detail in this leaflet, you may also find our Memorable Moments and Where to get help information useful. If you would like to find out more please get in touch.



*because
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This leaflet is available in different formats upon request.
Please contact the Marketing and Communications
Department for further information on 01284 766133.

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