

How to cope as a carer

作為一位照顧者該如何應對?

Mind HK was founded and is jointly supported by Mind UK and the Patient Care Foundation **www.mind.org.uk** • www.patientcarefoundation.com.hk • mind.org.uk

This booklet is for you if you are supporting a friend or relative and want to know how to look after your own mental health. It offers advice on how to look after yourself and where to get further support.

如果你正在照顧一個朋友或親戚,想知道怎麼維持你自己的心理健康,這本小冊子正是為你 而設。它提供關於如何照顧好自己的意見,和在飀 裡得到進一步支持的資訊。

Contents 目錄

What is a carer? 什麼是照顧者?	4
What challenges do carers face? 照顧者會面對甚麼挑戰?	5
How can I look after myself? 我可以怎樣照顧自己?	8
How can I get help? 我可以如何尋找幫助?	15
Self-help resources 自助資源	17
Useful contacts 常用聯繫人	26

What is a carer?

什麼是照顧者?

You are a carer if you are responsible for providing or arranging care for someone else who cannot care for themselves. A carer is not paid for their role, and is different from a paid professional like a care worker or home help.

You may already describe or think of yourself as a carer. However, you may not be sure if you are a carer or you may not like to use the term.

This booklet is relevant to you if you are supporting:

- · a family member such as your child, parent, sibling or other relative
- your partner
- a friend
- · a neighbour.

You may provide a range of support, including:

- giving emotional support
- helping someone cope with a mental health problem
- cooking and cleaning
- · personal care, like washing and going to the toilet
- budgeting and looking after finances
- · giving medicine or providing medical care
- interpreting for someone who is deaf or who does not have Chinese/ English as their first language
- reading information and filling in forms for someone who has literacy
- · or concentration difficulties.

Anyone can become a carer, no matter their age, gender or background. You may care for someone who has a long-term health condition or someone who

needs support after an accident or sudden illness. The care you provide could be short- or long-term. You may or may not live with the person you are a carer for.

"I was completely unaware that what I was doing was a carer role and of the effect it was having on me. I didn't think about reaching out for support for myself."

What challenges do carers face?

照顧者會面對甚麼挑戰?

Caring for someone else can often be demanding, and you are not alone if you feel overwhelmed at times. You might find some parts of life challenging and this may leave you feeling stressed and isolated. Over time, this can lead to mental health problems. If you already live with a mental health problem, being a carer could affect your ability to stay well. If you are caring for someone, you may face the following challenges:

Stress and worry 壓力和煩惱

You may often feel stressed and worried if you're caring for someone else. You could spend a lot of time thinking about their illness and the impact it is having on both of your lives. You may always be thinking about things you need to do as part of your role as carer, and find it hard to switch off. You may have difficulty sleeping, be eating too much or too little and find your mood is affected.

If you feel this way over a long period of time, it can have a big impact on your mental health and you can become unwell.

Social isolation 社交隔離

Many people find it hard to make time to socialise or carry on with hobbies or interests. You may also feel guilty if you take time for yourself. You may feel like your life is very different from other people's, and that

they don't understand how you are feeling. If you feel worried that you or the person you care for might face stigma, you may find it hard to let people know that you are a carer. This can make you feel very lonely.

Over time, social isolation can lead to mental health problems such as anxiety and depression.

You feel like your peers cannot relate to what you have to deal with at home. You are envious of people around you that have a 'normal' life, especially if you have no other family support.

Money worries 財政憂慮

You may find that you need to pay for extra care or medical costs. You may be spending lots of money on travel costs, especially if you don't live with the person you care for. This can put a strain on your finances, and may mean you have to cut back on other things, causing practical issues and additional stress. You may also find that you are not receiving enough financial support or benefits in order to meet these costs, and experience financial worries. Many carers struggle to cover costs, and get into debt.

Physical health problems 身體健康問題

Caring can be physically demanding. If your role as carer involves lifting or carrying, you could suffer from aches and pains, particularly in your back. You may feel run down and tired a lot of the time. This can make you more likely to experience physical illness, which could develop into a long-term problem. You may not have enough time to be physically active or to cook healthy food.

"Despite having physical health problems myself, I care for my sister and my elderly parents. I get so tired and have little help. I wish I could have a week off and just sleep. But you just have to keep going."

Depression 抑鬱

You may find that the challenges you face while being a carer make you feel low or depressed. If you feel very frustrated or hopeless, you may also have thoughts of harming yourself or even of ending your life. You may also develop unhelpful coping strategies to deal with these difficult feelings, such as using drugs or alcohol, or eating more or less than you need to.

Frustration and anger 失望和憤怒

You may often feel very frustrated and angry, especially if you have had to give up parts of your own life. Or, you might feel that you have been given no choice about becoming a carer.

You might end up directing this anger at family or at the person you care for. This could make you feel guilty.

Low self-esteem 自卑

Being a carer can have a big impact on your self-esteem. You may feel that you are not worthy of care and attention, and that all your time should be focused on the person you care for. You may find it hard to interact socially, or feel that you are missing out on parts of having a normal life.

You may lose confidence in yourself and your abilities to do anything outside of your caring responsibilities.

"I got no support and didn't really know there was anywhere or anyone I could turn to. It had a huge impact on my mental health. I developed obsessive compulsive disorder (OCD), anxiety and depression."

How can I look after myself?

我可以怎樣照顧自己?

When you are a carer you spend a lot of your time focusing on someone else. It can feel unnatural to think about yourself and your needs. But it's important that you look after your own wellbeing too. Taking positive steps to look after yourself can help you avoid physical and mental health problems. If you are able to stay well, you are more likely to be able to provide good support for longer, without getting too overwhelmed. So looking after your wellbeing is good for you and the person you care for. Here are some ideas about how to do this.

Try to stay healthy 盡量保持健康

If you are really busy, you might not always feel you have time to focus on looking after yourself. But it's important that you make time to look after your physical health, and there are lots of things you can do to improve it.

For example:

- Eat healthily try to eat regular meals, with plenty of fresh fruit and vegetables. It may help to plan your meals and make extra portions that you can keep for when time is short. If you find you forget to eat, try sticking a reminder on your fridge, or an alarm on your phone. (See Mind UK'sleaflet Food and Mood for more information.)
- Get enough rest lack of sleep can make it more difficult to cope with day-to-day challenges, and make stress and depression worse. There are lots of positive steps you can take to improve your sleep. You may find that you need to change your sleep pattern, for example sleeping for four hours twice a day, rather than trying to get eight hours, sleep every night. This could help you feel less worried about not getting enough sleep. (See Mind's booklet How to cope with sleep problems for more information.)

- Do regular physical activity even a short walk can be good exercise and can help you clear your head. If you struggle to get going on your own, you could join a class. If you find it hard to make time for exercise, try to build it into your daily routine, for example by walking to work rather then taking a taxi. (See Mind's booklet Mind tips for better mental health: physical activity for more information.)
- Look after your general health and wellbeing take time to notice when you are becoming unwell and try to take a break. For example, if you tend to develop cold-like symptoms when you are getting ill, take a break next time you notice that you feel this way. (See Mind's booklet How to improve and maintain your mental wellbeing for more information.)

Share your feelings with someone you trust 與你信任的人分享你的感受

It can be really important to have someone to talk to, especially if you're struggling to cope. Think about the people in your life you can turn to for support. You may have a family member who helps you relax, or a friend who is good at taking your mind off things.

You may find it hard to ask for help or tell people how you're feeling. Time to Change has some ideas about how you can start the conversation (see 'Useful contacts' on p.26). If you don't have time to meet up with people, you could try to stay in touch by email or text, or use online video chat.

Learn a relaxation technique 學習放鬆技巧

Using relaxation techniques can help you feel more rested. They can also help you make time for yourself. Most of the techniques here can be practised for a few minutes a day, so they don't have to take lots of time if you're struggling to make space for activities.

Yoga, meditation and mindfulness are all techniques you can use to relax

and to help switch off from your caring role. Search online for a yoga or guided meditation class in your area. If you can't go to a class, you can find videos and websites with instructions online. Mindfulness is a therapeutic technique that involves paying attention in a deliberate way.

Take a break 休息一下

Try to take a break when you need it, especially if you are worried about your own mental health. Having some time away from caring can help you feel refreshed, and enable you to manage your own mental health.

It can be hard to make a decision about when to take a break, especially if you feel guilty or worried about what will happen to the person you care for while you're not there. You may feel more able to take a break if you ensure that the person you care for knows what to expect and has any other support they need. This may mean asking the person you care for to find ways to cope without you for a while, or arranging for family and friends to help cover your caring responsibilities. If you need some help to organise a break, you could find out more about respite care (see p.16) or ask your local social services for support.

The length of your break will depend on how you are feeling. You may only need an hour or two to clear your head, or a day to help you feel more rested. You could go out, take a bath or turn your phone off for an agreed period of time.

It may be helpful to build a regular break into your routine. This can help you make plans in advance, give you something to look forward to and ensure that the person you care for knows what to expect.

You may find that you need a longer break, especially if you are worried you might be becoming unwell. At this stage, you may want to think about respite care (see p.16).

Make time for yourself 為自己留時間

Spending quality time with your partner, family or friends can give you a break from your caring responsibilities, help you stay positive and boost your confidence. Try to make time for the things that you enjoy, for example going for a coffee or a short walk.

Take time to pursue hobbies and activities that interest you or make you feel fulfilled. Try to do something regularly, like a yoga class or going to the cinema with a friend.

"I get up half an hour early to do my own thing and start the day as I like to."

Try to be organized 嘗試有條理的生活

Finding a way to feel in control of your responsibilities can help you manage feelings of stress and anxiety. You could:

- Make a schedule or planner keeping a schedule of the key parts of your day-to-day routine, such as bathing, cooking or taking children to school, can be very helpful. You could also plan in more detail, for example, by keeping shopping lists and a schedule of meals if cooking is part of your role as a carer.
- Keep important information in one place for example, emergency contact details and information about medication (see 'Self-help resources, on p.17). You could make sure someone else (such as a social worker, friend or family member) also knows where this information is kept in case it is needed when you are unwell or not at home.

Be realistic about what you can do 現實地瞭解自己可以做的

It's important to be realistic about what you can do. If you take on too much, you may feel like you never get to finish or achieve anything. You

may want to make the person you care for better or take away the impact of their illness, and feel very upset that you can't. This can lead to stress, anxiety, guilt or low self-esteem. Having a clear idea about what you can do, and accepting parts that you can't change or do alone, helps to reduce this stress and can make you feel more able to cope.

You might find it helpful to:

- Make a list of the kind of support the person you care for needs this
 helps to identify what needs doing and can give you a clearer idea of
 how much support the person you care for needs.
- Identify what you can do, and what you need help with. Work out a plan
 with the person you care for about who will provide the care you can't.
 For example, you may need medical support or some professional care.
- Think about how you will be able to tell when things are getting too much and you need a break. For example, you may struggle to sleep when you're feeling low and this could be something you notice as a sign that you need a break. You could write these signs down as You may also want to share them with someone you trust and ask them to let you know if they recognise that you are becoming too stressed and need a break.

Make sure you have all the information you need 確保你有你所需的所有訊息

Making sure you have access to reliable, clear information can help you feel more in control. This could be medical information about any diagnoses the person you care for has, or advice about your rights. If you're not sure where to find this, looking online or asking your GP are both good starting points. Plan for appointments and take notes of things you want to talk about. This will help you remember what you want to say and to get the information you feel you need.

Medical language can be really complicated, so don't be afraid to ask for further explanations if you don't understand.

Information about medical treatment 有關醫療資訊

"The person I am caring for wants me to know about their treatment. "

Make sure that the person you care for has told any medical professionals, social workers and support staff that they are happy for you to have access to your medical information. You could ask for a note to be put on any records confirming that you have permission to see them.

"The person I am caring for does not want me to know about their treatment."

If the person you are caring for does not consent to you receiving information about their treatment, you may still be able to receive general information. For example, a doctor may give you information about a health problem, but not specific details of the treatment that is being offered.

It's important that you are given the information you need to provide care safely and effectively. If you are concerned that you or the person you care for will be put at risk because you do not have essential information, you should raise this concern with any medical staff involved. They will agreement of the person you are caring for.

Find positives in your relationship 在你的關係中尋找正面的事情

Being a carer can have a big impact on the relationship you have with the person you support. Sometimes you may feel very close and connected, while at other times you may feel distant or irritated with each other. It can help to talk openly and honestly to find ways of coping with these challenges together.

For example, you could try to:

• talk to each other about how you will strengthen and maintain

positive parts of your relationship see each other as whole people, with interests, characteristics and hobbies

- think of yourself not only as their carer but also as their friend, partner or family member
- try to do nice things together, as well as carrying out day-to-day responsibilities – this will help maintain your relationship outside of being a carer, and help you connect on a different level
- think about what you get out of caring, and write down a list of positive things that you can look at when you are feeling frustrated or low
- recognise practical and specialist skills and knowledge you have gained, or people you have met that you wouldn't otherwise get to know.

Focusing on these positives can help you feel that you have a deeper relationship and understanding of the person you care for, and appreciate that they may feel this way about you too.

"I would urge anyone who is a carer to try to see the positives in your situation and to realise you are there out of love and respect for the person you are caring for."

Support the independence of the person you care for 尊重你照顧的人的獨立性

Work with the person you care for to see how they can help themselves. Together you may be able to enable the person you care for to make some decisions about their care on their own, and identify times they can cope on their own. It is important to try to respect the opinion of the person you care for and help them have some control over their care. This could mean making sure their wishes are expressed to doctors, or letting them try activities on their own. You may find that this means taking a step back, or supporting decisions that are not what you would do. But this could help the person you are caring for feel respected and in control.

You may also find it helpful to talk about what support they would like from you. This may change over time, so it's worth revisiting this conversation.

Make a crisis plan 做一個危機計劃

If you are concerned about what would happen if you become unwell, having a crisis plan in place can help to reduce stress (see 'Self-help resources 'on p.17).

Thinking about the following things when you are well can help you feel prepared for a crisis:

- Discuss what will happen in an emergency with the person you care for, and agree a plan with friends, family or paid care workers.
- Write a list of who should be contacted in the event of an emergency and keep it somewhere easily accessible.
- Leave details about your caring responsibilities, such as medication you normally give and ongoing treatment the person you care for is having, and make sure someone else knows where this information is. This could be a friend, family member or health or social care professional.

How can I get help?

我可以如何尋找幫助?

You may feel that you need additional help to cope with being a carer. There is a range of options available for getting help and support.

Peer support 同濟的支持

Social media like Facebook has been really helpful to get emotional support from friends. "I wish I'd have had Twitter when I was younger, it would have been a great way to vent frustration and talk to others in a similar place."

If you think you might need medical help or that you might be experiencing a mental health problem, the first step is usually to talk to your GP. They will be able to talk about treatment options, which could include talking treatments

or medication. Your GP should also be able to help you identify ways of getting support, including local carers' services and social care support.

Talking treatments 你的醫生

Talking treatments provide a regular time for you to talk about your worries and explore difficult feelings with a trained professional. You might find it particularly helpful to be given the space and time to talk about how being a carer affects you, without having to feel guilty for expressing parts that are difficult or frustrating. This can help you to deal with specific problems, cope with a crisis, improve your relationships or develop better ways of living. (See Mind's booklet Making sense of talking treatments for more information.)

Your GP or social services will be able to give you more information and tell you how to find a therapist. Therapists will also be able to tell you about the kind of support they offer and whether it will be useful to you.

Respite care 照顧者評估

You may be entitled to support to help you have a break from caring. This is known as respite care. It could happen regularly or as and when you need it.

Respite might include:

- your local authority arranging for someone to take over your caring responsibilities for an agreed period of time
- support for you, from a local authority or charity, to take a holiday
- paying a professional carer to look after the person you support so you can have a break, for a long or short period of time.

If you have a carer's assessment, it should include information about respite care. Some voluntary organisations also provide respite services. Your local Mind or social services will be able to give you more details.

Social care support

談話治療

Social services can provide support to you and the person you are caring for. They may be able to provide practical support or put you in touch with a support group.

The kind of support you are offered will depend on your needs and the needs of the person you care for, but could include:

- equipment
- technology such as adapted telephones or monitoring devices which help people stay as independent as possible
- respite care (see below)
- professional care workers, sometimes known as 'home help'.

Support at work

暫托服務

If you are finding it hard to balance paid employment and your caring responsibilities, you can ask your employer if you are entitled to flexible working arrangements. This could include going part time, changing your working pattern or job-sharing.

Self-help resources

自助資源

These sections are for you to print or download and fill out. Put them in a prominent place, like on the fridge, and look at them when you're feeling stressed.

You may also want to share this information with other people who offer you support, so that they know what you're doing as a carer and can recognise the signs if you are struggling.

Mhon	thin a		anin a	المبيد
When	UTITIC	js are c	JOHIC	weii

Write down the things you need to happen for you to feel that you are coping as a carer.

- "The person I care for's GP is really helpful"
- "I am communicating well with the person I care for and we both have realistic expectations"
- "I have support from my friends and family"
- "I am meeting all my targets at work"

·

Things that help me stay well

Write down the things that you do for yourself that make you feel happy and well. These could be small, day-to-day things or longer term achievements.

- · Making the bed
- Making sure I eat breakfast
- Going for a walk each day
- Chatting to other carers online
- Reaching a goal e.g. completing a language course or running a certain distance

·	

Daily planning 日程計劃

Write down what you do each day, week or month. This could include things you do as a carer, and things you do for yourself.

Example	As a carer	For myself
Every day	Cooking Giving medication Helping with getting dressed	5 minutes of mindfulness Reading a book
Weekly	Driving to therapy Helping with coursework	Yoga class Carer's group
Monthly	Accompanying to doctor's appointment	Night out with friends
Other	Carer's assessment	Holiday

	As a carer	For myself
Every day		
Weekly		
Monthly		
Other		

Situations that can make me feel stressed or overwhelmed 使我感到緊張或不知所措的情況

Write about the times you find it hard to cope as a carer, and any previous actions you have taken that have helped.

- I am really tired and not sleeping well
 I can try: having a bath, playing calming music
- I don't feel like professionals are helping me to cope
 I can try: making a list of things to discuss before my next appointment
- I'm worried about money
 I can try: Setting a realistic budget, getting some support from a money advice service

How I can tell when things are getting too much? 我怎麼知道事情超出我的能力範圍

Think about how your behaviour and habits change when you are finding things hard. You may want to show someone else this section, so that they can recognise the signs that you need support.

- I can't sleep
- · I eat and drink too much
- I feel angry and snap at the person I care for
- I get headaches

What I can do when things are getting too much? 事情超出我的能力範圍時,我可以做甚麼?

Write down things that have helped you feel better when you have previously felt overwhelmed, or ideas of what you could do when problems arise.

- Work out what I need to do and what will wait until I feel better
- · Ask a friend or family member for help
- · Let the person I care for know that I'm struggling
- Take some time before going to bed to reflect on the day and make a 'to do' list so that I'm not worrying while trying to sleep
- Make sure I have healthy food at home and drink lots of water

In an emergency 緊急情況下

Use this section to record any information you might need in an emergency.

- Emergency contacts, for example GP, crisis team, out of hours services
- Contact details of friends and family who can help in a crisis
- Essential information about you and the person you care for such as medication, schedules, contact phone numbers, details of their health workers

Useful Contacts

有用的聯絡

The Mental Health Association of Hong Kong
香港心理衛生會

Tel: 2528 0196

Web: www.mhahk.org.hk

HK FamilyLink Mental Health Advocacy Association

香港家連家精神健康倡導協會

Tel: 2144 7244

Web: www.familylink.org.hk

United Centre of Emotional Health & Positive Living

聯合情緒健康教育中心

Tel: 2349 3212

Web: www.ucep.org.hk

Amity Mutual Support Society 恆康亙助社

Tel: 2332 2759

Web: www.amss1996.org.hk

The Samaritan Befrienders Hong Kong 港撒瑪利亞防止自殺會

Tel: 2389 2222

Web: www.sbhk.org.hk

Institute of Mental Health Castle Peak Hospital 青山醫院精神健康學院

Tel: 2466 7350

Web: www3.ha.org.hk

Further Information

Mind HK was founded and is jointly supported by Mind UK and the Patient Care Foundation. At the moment Mind HK is limited to website support but with donations we hope to expand the work that is done. Volunteers welcome to contact:

mentalhealth@patientcarefoundation.com.hk

Mind Hong Kong 是由 Mind UK 及Patient Care Foundation Hong Kong 聯合協辦的機構。在現階段我們只能提供有限度的網上支緩。假若有足夠的捐款,我們會進一步擴大服務範圍。如有興趣參與義工團隊,請聯絡: mentalhealth@patientcarefoundation.com.hk