

A guide to using Carer Support

How full-time unpaid carers can access a subsidy
for rest and relief



Contents

Are you an unpaid, full-time carer?	3
To care well for someone else, you need to look after yourself too.	4
How can I use Carer Support?	5
How does Carer Support work?	6
Am I eligible for Carer Support?	7
Am I a full-time carer?	8
Frequently asked questions	9
How do I claim for Carer Support?	12
Useful contacts	15

Are you an unpaid, full-time carer?

Providing full-time care for a person with a long-term disability or chronic health condition can be hard work. There will be times when you need a break. It's important to get some help.

Help is available

Carer Support offers you a break by contributing to the cost of someone else looking after or being with the person you care for, while you do something else or just rest. It is not a wage or a salary but an assistance towards the costs of providing some support care to relieve you.

“ You are free to decide what best suits your needs and wishes. ”

This relief care is for a certain number of days each year, based on the assessed needs of the person you're looking after.

If you are eligible, a Needs Assessment Service Coordination agency will do a needs assessment of the person you care for and allocate Carer Support to you. It's up to you to decide how you will use it. You and the person you're caring for have the right to make this decision. In most cases, you can coordinate your own relief care.

Why is Carer Support important?

It's important to take a break because this enables you to keep providing support to the person you're caring for so that they may continue living at home for as long as possible. It also provides you with the opportunity to do things for yourself.

Who provides Carer Support funding?

The District Health Board, with Ministry of Health funding, provides this financial support for full-time, unpaid carers. With this assistance, you can continue looking after the person in your care. You don't miss out on any extra help!

What is the payment rate?

Check with your local Needs Assessment Service Coordination (NASC) agency or District Health Board for payment rates as these can vary from region to region.

About this guide

This guide provides information about Carer Support. You can find out if you're eligible for this funding, how it is allocated, the different ways Carer Support can be used to suit your own needs, the payment process and how to make a claim.

To care well for someone else, you need to look after yourself too

If Val had only taken a break...

Val was a wonderful wife, dutiful and caring. Aware that her husband James was displaying symptoms of Alzheimers long before his diagnosis, but not wanting to upset him, she covered up by taking over more and more of his chores and answering questions for him.

For two years following his diagnosis Val cared for James full-time. She had little support as her adult children all lived in other towns or countries. She was allocated respite days by a Needs Assessment Service Coordination agency and at one stage planned to use them. But James became agitated and upset when she arranged to leave him at the local rest home for a few days so Val changed her mind and cancelled her plans.

Time and again her Dementia Waikato support coordinator urged her to take some of her well-earned Carer Support days. Stressed and exhausted, Val desperately needed a break but out of duty and love for her husband Val wouldn't leave. Then suddenly everything took its toll. Val, who had no previous history of heart problems, had a heart attack. While she was hospitalised James was put into full time residential care. Even after her discharge from hospital James wasn't able to come home. He is still in care today and Val is still grieving her loss.

David made full use of his Carer Support

David's wife Cath was 66 when she was diagnosed with Alzheimers. Although several years her senior, David was determined to take care of Cath for as long as possible.

Once the daily care of his wife began to take its toll on him he agreed to make full use of his respite care – both in home support and time in a residential care facility. David had his regular hobby time out with his club while someone cared for Cath at home. He regularly took breaks to go and stay with family/whānau members while Cath spent time in a residential care facility.

As time went by David accepted more and more services, including help with her personal care. He also accepted all the support he could from the Dementia Waikato team and learnt to understand the way his wife perceived the world, and to use strategies that minimised conflict and misunderstanding.

David was able to keep Cath at home for eight years after her diagnosis and by the time she went into full time residential care she was in the very advanced stages of the illness, totally immobile and unable to communicate. Although this was still traumatic for David, he knows that he did all he could for Cath for as long as possible.

“I got some help and I thought, Why didn't I do that years ago? It really is okay. It's not a sign of not coping. It's intelligent.”

How can I use Carer Support?

Carer Support is a form of relief to full-time carers and it's important that you benefit from it. How you use your Carer Support days is up to you and the person you care for. You're free to decide what best suits your needs and wishes. Carer Support is flexible. There are different ways to use your allocated days.

Carer Support can be provided:

IN YOUR HOME. This means you can either go out or stay home and do other activities while support is being provided. It is usually better to leave home as you're more likely to get a complete break.

If there's a special activity you like to do you should go out and enjoy it. It's a great way to relax and take your mind off things. You might like to keep on with a favourite pastime, or try a fun new activity, join a club, get your hair done, visit a friend, take a long weekend or go on a trip. It's all about having some "me" time and reminding yourself that you count too.

IN THE COMMUNITY AWAY FROM THE HOME. By having a support carer take the person you care for out, you get a break at home or you can go and do what you like.

The person you care for may enjoy an outing to the park, or going to a club, the movies, beach or shops. Perhaps there is another activity outside the home they would enjoy? There is also a range of day activity programmes, recreational, sporting or therapeutic activities that are provided by skilled specialists or voluntary organisations. Arrange a support carer to make this happen. Meanwhile, you can stay home and put your feet up, potter around in the garden, or go out. This is your time to relax and re-energise.

IN ANOTHER DHB REGION; for example, if you have friends or family/whānau living outside of your area. Carer Support can be used anywhere around the country.

If they're up to it, this is a wonderful opportunity for the person in your care to spend time away with other family/whānau members or friends. The change of scene will do them good and the rest will benefit you.

IN A FACILITY, such as a residential care facility or day care centre. You can recharge your batteries while the person you care for is away from home. Make the most of these quiet times by resting yourself.

A facility worked well for Mary and Peter

Since suffering a stroke five years ago, 75 year old Mary requires full-time support. She lives with her husband Peter in their own home where, together with support from caregivers, he's able to provide this support. Their daughter lives nearby and visits regularly. But recently Peter was admitted to hospital after a bout of pneumonia then later discharged to a rest home for transitional care. Mary was unable to remain at home alone and her daughter couldn't provide her with full-time care because of work commitments. Mary and Peter decided to use their Carer Support days for Mary to have some respite in the same facility with him.

How does Carer Support work?

You can claim a subsidy towards the costs when you've arranged Carer Support for the person in your full-time care and need to pay for this support.

You can choose who provides the Carer Support:

Informal carers

- Friends, neighbours, people you know.
- Family/whānau not living at the same address as the person being cared for.

Formal carers

- A home support agency or organisation that can provide trained carers.
- A residential care or dementia care facility or day activity programme.

You can choose how much Carer Support is provided at any one time

- Use as little as 1 hour at a time.
- A 'half day' is 4 - 8 hours.
- One 'full day' is any time 8 - 24 hours.
- See page 13 for help calculating your Carer Support hours.

Carer Support is not a wage. It's financial assistance, a subsidy providing a contribution towards the costs associated with receiving support care. The 'half-day rate' provides for up to 8 hours of care but is not meant to be equivalent to a wage.

Generally friends, neighbours or family/whānau members (informal carers) are happy to provide care and just receive sufficient payment to cover their transport, any other costs incurred and perhaps some acknowledgement for their support – and that will be covered by the Carer Support rate.

However there will be times when you need to use carer services outside your circle of family/whānau and friends.

When paying for formal care services, you may need to add money to meet the rate they charge for their services, or perhaps adjust the number of hours you expect them to work.

Whatever you do, it is important to agree on the payment rate and hours right from the start. Misunderstanding and conflict can be avoided if you're both clear about your expectations.

If you are eligible to use hospital level care or dementia care in a residential facility as your Carer Support, then the District Health Board will provide a "top up" at no cost to you (see page 12).

Am I eligible for Carer Support?

The first thing to do is to arrange a needs assessment through a Needs Assessment Service Coordination agency.

You can receive Carer Support if:

- the person you're looking after is 65 years or over and has an age-related disability that is likely to continue for at least six months;
- it can also include people aged 50 - 64 with age-related needs, such as early dementia;
- the person you're caring for is under the age of 65 years and has been identified as having a chronic health condition and is in need of long-term support;
- you are a full-time unpaid informal carer;
- you have been approved for 'Paid Family Care' but also provide unpaid care.

Eligibility for Carer Support is not attached to you, but to the person you're caring for. Carer Support remains with them even if there's a change in their full-time carer.

USE THEM OR LOSE THEM! Carer Support days can only be used during the 12-month period for which they are allocated. Any days that are left over can't be carried through to the next year. So make sure you use them within the allocated time period.

PLAN AHEAD. Once your Carer Support days have been allocated it's a good idea to plan your year ahead. This is the best way to get the maximum benefit from your relief days. You can split your days over the year and choose when to take a break.

Planning includes booking support carers and beds at care facilities where possible.

HELPFUL HINTS

- Match the care to when you need it and how often
- Match the support/relief carer to the person you care for
- Match the relief care to the interests of the person you care for
- Don't leave it too long before taking a break
- Get help from the Needs Assessment Service Coordination (NASC) agency to make Carer Support happen when you need it

Am I a full-time carer?

You're a full-time carer if:

- you're providing full-time unpaid care (i.e. for 4 or more hours each day) for a person with a disability in their own home, or your family/whānau home, and that without this level of support the person you're caring for couldn't continue to live at home. You are eligible for the Carer Support days so you can have a break.

However if you are in paid employment, you cannot use Carer Support during the hours that you are working.

Mary is married to Ron. Ron has moderate dementia and is not safe to be left on his own. Mary has a part-time job and enjoys her work as it gives her a break from looking after Ron. Ron can access day care and have other home supports while Mary is at work, but not through the use of Carer Support days. Mary could talk to the Needs Assessment Service Coordination agency about getting Carer Support days if she feels she needs a weekend break away now and then, or to allow her go out in the evenings sometimes.

Can Carer Support be paid to other family/whānau members?

Carer Support cannot be used to pay the spouse, partner or parent/step parent of the person being cared for. Any other family/whānau members can be paid Carer Support – so long as they are not living at the same address as the person being cared for. However in some exceptional circumstances this may be waived if approved by the DHB Needs Assessment and Service Coordination agency.

What happens if there's a change in full-time carer?

You must let your Needs Assessment Service Coordination agency know of any changes as soon as possible. Once they've been informed, the Ministry of Health Carer Support office will send a new claim form to the new full-time carer (unless all days for that year have already been used up and claimed for).

How long should I wait between Carer Support breaks?

This depends on your personal circumstances; each situation will vary. But keep in mind that you should plan frequent breaks and not wait until you're completely worn out before taking a break. For example, you can use Carer Support for a break of a couple of hours each week while you have a social outing or time to be at home by yourself.

Your extended family/whānau may be able to help you identify times when you should take a break.

Although you may have a strong duty to care ('... in sickness and in health...') you still deserve to take a break. By taking some time out you'll feel more energised and refreshed to resume your care role. Looking after yourself is very important. Then everyone benefits!

“Although the full-time unpaid care may be shared by a number of carers, there must be one carer classed as the full-time carer, or primary carer. The number of carers is usually no more than two or three.”

Frequently asked questions

1. What is the Carer Support rate?

You can find out the amount of the Carer Support subsidy in your region by contacting your Needs Assessment Service Coordination agency or the District Health Board.

2. We live together and both have disabilities. We provide mutual support for each other. Can we get Carer Support?

You may be eligible. Talk about your situation with a service coordinator at a Needs Assessment Service Coordination agency.

3. How do I find a support carer?

Very often family/whānau and friends will be willing to help and may not realise you would like them to assist. If they are not an option, contact organisations that have volunteer services, or have employed carers, like home care services. Your Needs Assessment Service Coordination agency may be able to suggest some options, or try some of the useful contacts on page 15.

4. What if a crisis situation occurs? Can I receive extra home-based services?

A temporary increase in home-based services may be considered, but firstly the person you're caring for will need an emergency reassessment from a Needs Assessment Service Coordination agency. This referral should take place within one working day. After reviewing your changed circumstances, your Carer Support allocation may be extended.

5. Can people living in residential care facilities receive Carer Support?

No, not if they are living there permanently.

Yes, if they are only there temporarily and return home after the period of care.

6. I am recovering from surgery. Is Carer Support available?

No. However, if you are a full-time carer yourself and you're unable to provide care to the person you look after, Carer Support may be able to be provided for their care.

7. I am being paid by the Accident Rehabilitation and Compensation Insurance (ARCI) Act 1992. Am I also entitled to Carer Support?

No.

8. Can a formal carer who is already being paid to provide support to a person receive Carer Support?

No.

9. What do I do if I don't want to have strangers in my home but I still need a break?

For your own well-being, taking a break should be your priority. Rest assured that if you are not using family/whānau or friends and have arranged support carers from an organisation they are usually very professional and well qualified. If you have doubts, talk to your local Needs Assessment Service Coordination (NASC) agency or Dementia Waikato team.

10. The person I care for goes to a rest home every so often to give me a few days break, but they always comes back disoriented and upset and so I don't really get a proper break. What would help this situation?

Be prepared for this situation. Have a friend or family/whānau member to assist with chores over the first few days when they come home. This will allow you to spend more time with the person you care for and ease their transition back into the home. Look for providers who can keep the person you care for mobile and active during their stay.

11. I worry that the person I care for will need help that the support carer isn't able to provide as well as I can.

If your support carer is from a professional agency, they will have the training and experience to cope. If your support carer is a friend, family/whānau member or neighbour, it's likely they're already familiar with the needs of the person you're caring for. Trust that they will do a good job. Provide them with all the relevant phone numbers, e.g. doctor, service co-ordinator, support agencies, family/whānau members and have medications organised. Pharmacy packed medications will reduce risk of errors.

12. What do I do if I suspect that the support carer is making fraudulent claims?

Claim forms need to be signed by yourself and the person who has provided the support. If you have concerns, you should raise them with the support carer first. Explain to them what you're concerned about, and why. If you still have doubts about their integrity or feel you're unable to resolve the problem yourself, contact Health Consumer Service on 0800 801 482 or the Ministry of Health Carer Support Service 0800 281 222 (press 1). Making false claims is a criminal offence.

13. Can a family carer living at the same address who is being paid to provide support to a person receive carer support?

In some very exceptional circumstances under the DHB's 'Paid Family Carer Policy' – your local Needs Assessment and Service Coordination agency will clarify this.

14. What do I do if I suspect abuse (e.g. verbal or physical abuse) is occurring while I'm away?

Speak directly to the person first. Gather as much information as you can. Try and get all the facts. Discuss your worries with a family/whānau member or contact Health Consumer Service on 0800 801 482, Age Concern, or your general practitioner. If the support carer is employed by an agency, contact the agency directly. Remember that you need to be sure about the allegations before taking further action. It is not okay to tolerate abuse of any kind.

15. What do I do if I'm worried about the support carer taking advantage of us e.g. the person who I care for lent the support carer our eftpos card to get some petrol when they were on a shopping trip last week?

Speak directly to the person first. Gather as much information as you can. Try and get all the facts. Discuss your worries with a family/whānau member or contact Health Consumer Service on 0800 801 482 or Age Concern. If the support carer is employed by an agency, contact the agency directly.

16. What do I need to do to make it easier for alternative carers / respite services?

Ensure information is given on the person's likes and dislikes, that medications are pre-packed and contact details of key people are provided, e.g. yourself, G, other family/whānau members.

17. It's such a hassle to fill in the forms, where can I go to get help?

Filling in forms can be overwhelming. The Ministry of Health supplies a guide to help you complete your Carer Support claim but you may prefer to ask a family/whānau member for assistance. The Needs Assessment Service Coordination agency and Dementia Waikato team, or the Ministry of Health 0800 281 222 (press 1) also provide advice.

If you have an informal private person as a support carer coming into the home, this is an arrangement between you and them. If you're using an informal carer, you are responsible for monitoring the quality of their service. You can put a stop to it any time you like. There is no need to go on with the arrangement if you're uncomfortable or unhappy about it. If there is a problem, the best thing to do first is talk to your support carer and find out the facts. There may be an easy solution.

If there is a problem with a formal provider, you could speak to the provider's management first, or the actual carer. If the issue is serious and is not resolved at this level, you will need to contact a health consumer service such as Age Concern or the Health and Disability Commission on 0800 11 22 33.

How do I claim for Carer Support?

STEP 1: After the Needs Assessment Service Coordination agency has completed your needs assessment, the Ministry of Health will send you an information pack in the mail containing carer support claim forms.

STEP 2: After you have used carer support, complete the claim form and return it to the Ministry of Health.

STEP 3: If you need assistance, talk with your Needs Assessment Service Coordination agency or the Ministry of Health (0800 281 222 press 1).

KEY POINTS

If you choose Carer Support at home:

- If the cost of the care is greater than the District Health Board subsidy per full day, you will have to pay the difference. Paying the difference is your responsibility.
- If the person providing in-home care support is GST registered for Carer Support (e.g. they are from an agency or self-employed), you must attach their tax invoice with any claim. (A tax invoice shows the "plus GST" amount separately from the total charge or has a note to say the total includes GST).

If you choose a residential facility for Carer Support:

- If you've been assessed as eligible for Carer Support at either hospital level or dementia level of care in a residential facility, the District Health Board will pay the difference in cost between your Carer Support daily contribution and the bed-day rate for the level of care that is required. This is often referred to as a "top-up." There will be no cost to you.
- Remember to tell the facility that you've got approval when you arrange the stay.
- Remember to take a Carer Support Claim Form with you each time because the facility has to complete the paperwork, sign the form off and send it to the Ministry of Health.
- Each day the person in your care spends in the facility counts as a whole 'allocated day', regardless of the time they arrive or depart.
- If you arrange for additional services (such as outings, hairdressers) that are not part of the usual care services you must pay for them.

You only receive payments for the number of Carer Support days allocated to you by a Needs Assessment Service Coordination agency. If you want to purchase additional days of support, you will have to pay for them yourself.

If you think you need more Carer Support days allocated to you, contact your Needs Assessment Service Coordination agency.

Who receives the payment?

- Payment is made either directly to the person or organisation that has provided the support care, or to reimburse you as the full-time carer if you have already paid the support carer. Make sure each of you is clear about the payment arrangement from the start. You must both agree as to the method of payment.
- As payments are made by direct credit, bank verification is required for yourself or others you are paying who are not already set up for payments from the District Health Board. This verification can be a bank printed deposit slip; the top of a bank statement showing your/carer's name and full bank account number; or some other form stamped by the bank showing your/carer's name and full bank account number.

When do I claim for Carer Support days?

You can only make one claim at a time so if you use different support carers or a mixture of support at home and support in a residential care facility you need to make the claims as each episode of care is completed, or when the care adds up to 4 hours or more from that agency or person.

The minimum unit you can claim and be paid for is a half-day. A half-day is 4 hours up to 8 hours. If you have a support carer in for only 1 or 2 hours, you need to add up these hours until they make up a half-day or a full day, then you can claim for them. Here is an example:

CLAIM DETAILS

Date(s) of service	Hour(s) if applicable	Half days	Full days
31/05/12	1.5 hours (1)	-	-
01/06/12	2 hours (2)	-	-
02/06/12	1.5 hours (3) →	1 (4)	-
15-16/06/12		-	2 (5)
Total days claimed			2.5 (6)

*Numbers in brackets e.g. **(1)** refer to the explanations below.

1. Your support carer came to your home for one and a half hours while you went out. You noted the time and date on your Carer Support Claim Form.
2. Your support carer took the person you care for on an outing. The time and date were recorded on your claim form.
3. You visited a friend while your support carer stayed in your home to provide care. Your one and half hour break was noted on your claim form.
4. Over the past 3 days you've accumulated 4 hours of carer support hours. You can now claim for one half day.
5. You received 2 full days of support care and recorded them on your claim form.
6. You can now submit a claim for 2.5 days of Carer Support.

Continued on page 14

Tips and instructions

- Check that the form is filled out correctly and all the information is complete and correct.
- Only claim for the days allocated to you. Making false claims can result in legal action to recover funds, as well as criminal prosecution.
- If there are any changes or corrections on your claim form they must be signed by both the full-time carer (you) and the support carer.
- Make sure that both you and your support carer have signed the form.
- If you had more than one support carer, a separate form must be completed for each support carer.
- Return the completed form to the Ministry of Health within 90 days of receiving your last Carer Support service.

What is the difference between a formal and an informal provider?

A FORMAL PROVIDER is a person or organisation that is GST registered. Formal providers, such as residential care facilities, day care centres and professional home care agencies, are eligible for the formal rate of payment.

If your support carer is a formal provider you must attach a tax invoice to your Carer Support Claim Form. This invoice will show the GST amount separately from the total charge.

Residential care formal providers will take the signed carer support claim form and complete the invoicing process for you. A new claim form showing the remaining entitlement will then be sent directly to you.

AN INFORMAL PROVIDER is a person or organisation that is not GST registered for Carer Support. They provide care in an informal setting such as your home. Your friends, family/whānau and neighbourhood volunteers are likely to fall into this category. If your support carer is an informal provider there is no need to submit a tax invoice.

HELPFUL INFORMATION:

- Payments are usually made within 10 working days of receiving a correctly completed form.
- You will receive additional Carer Support Claim Forms as your claims are processed throughout the year, so long as there are still carer support days to use.
- You can ask for a replacement form at any point by phoning 0800 281 222 (press 1).
- An incorrectly completed or late Carer Support Claim Form slows down the payment process. If you're unsure how to complete the form, ask for help. Your Needs Assessment Service Coordination agency team can assist you, or perhaps a friend or family/whānau member.
- It is the support carer's responsibility to contact the Inland Revenue Department about their tax obligations.
- Check with your local Need Assessment Service Coordination (NASC) agency or District Health Board for payment rates as these can vary from region to region.

Useful contacts

Age Concern

www.ageconcern.org.nz

Works for the rights and wellbeing of older people. Local branches can be found in the phone book or on the national website.

Carers NZ

www.carers.net.nz

Information and support for those who are caring for family members or friends. Includes a "Help and advice" section.

Dementia Waikato

07 929 4042

www.dementiawaikato.org.nz

Information and support for those who are caring for people with dementia-related disorders.

Eldernet

www.eldernet.co.nz

Includes a directory and information about residential care facilities, home help organisations, respite care, and other useful community contacts.

Seniorline

0800 725 463

www.seniorline.org.nz

National information service to help older people navigate the health system and make decisions about staying at home, care options etc.

