

GBS/CIDP Case support from State institutions

There appears to be Seven Sources of potential help

1. ACC
2. WINZ
3. Local D.H.B
4. Ministry of Health Disability Support Services
5. Support Service Providers
- 6 “Voluntary” Organisations
7. Charitable Organisations that will fund individuals with disabilities

Comments are generally directed at financial and physical assistance available to “typical” GBS sufferers (is there ever a “typical” case?) although, of course, the assistance availability guidance documentation available from official resources applies to a wide spread of health issues.

1. **ACC** – No chance of any help whatsoever unless can prove that an “accident” caused the onset of GBS – e.g. Flu Jab (Christchurch situation) – lengthy “proof process (which reflects ACC’s newly applied policy of challenging diagnosis and the use of the “age related” illness conclusion to avoid ACC assistance being granted) and whilst the only recorded case so far resulted in physical help (aids/home modifications, home help and physio) there is no evidence to date that the 2/3rds salary provision of normal accident situations for working personnel would apply. ACC **can** provide assistance in “disability” - non accident - cases to assist in transportation to and from work and the provision of special parking permits on a short or long term basis.
2. **WINZ** –5 main areas of assistance:-
All require claimant to be a NZ citizen or Permanent Resident – with at least 2 years living in NZ and over 18 years of age (generally).
Application must be made in person to your local WINZ office on the appropriate form. If the claimant is unable to attend (i.e. in ICU or otherwise “laid up” in hospital) they can appoint an “agent” – usually a close family relative – to progress their claim for them.
Claim eligibility is reviewed regularly (at least annually) and WINZ are charged with providing all the assistance they can to get claimants back into the workplace. There is also a presumption that if your spouse/partner is capable of working then they must make an effort to obtain work to support you – this would need to be set against the need for a home carer/support and a GP’s support may be necessary here to deflect WINZ’s actions.

2a. Sickness Benefit

Provides a financial benefit (around \$200pw after tax – but varies with personal circumstances) if you are temporarily unable to continue to work (full or part time) or, if unemployed at the time you get sick, prevented from seeking work as a result of your sickness or disability. If you have a partner they may be expected to look for work (full or part time dependent on family circumstances) .

It is not available if you have retired from the workplace.

Other sources of income (yours and your spouse/partner's are taken into account above \$80 pw) and will probably reduce the allowance paid. A medical certificate from your GP supporting your claim is a must have.

2b. Invalids Benefit

Provides a financial benefit (around \$260pw after tax – but varies with personal circumstances) if you are unable to work regularly 15 hours or more a week because of your sickness or disability and this is expected to persist for at least two years.

Other sources of income (yours and your spouse/partner are taken into account above \$100 pw) and will probably reduce the allowance paid. A medical certificate from your GP/Specialist or a report from a Needs Assessment Review is a **must** have.

2c Disability Allowance

A claim for this benefit may be accepted even though you are receiving assistance from Sickness or Invalids benefits. Maximum payment is around \$60 per week.

The disability must be likely to last at least 6 months and you need ongoing help or medical care.

If you are not already on another benefit then an income test is applied.

The allowance is primarily to cover the extra costs incurred as a result of the disability e.g. Doctor's or Specialist cost not already subsidized, Prescription fees, Travel costs to the doctor or hospital, heating costs, gardening costs and alarm rentals. It is essential to keep a record of your expenditure and all receipts!!

Special grants to cover the cost of visiting a partner in Hospital or towards the cost of home modifications may also be available but depend on individual circumstances.

2d. Community Services Card

A CSC **may** help reduce the cost of some health services e.g. prescriptions, after hours doctors visits or travel costs if you have to attend a hospital more than 80km from your local area. It comes automatically if you are on Sickness or Invalids Benefit – otherwise it is income tested on application.

2e Extra Help Supplements

Two main types:-

1. **Accommodation Supplement:** To assist with the cost of renting a home, boarding costs and the mortgage and rates cost on your own home.
2. **Temporary Additional Support :** To assist where you are finding it hard financially to manage.

Both supplements are income tested and you are expected to take every reasonable steps to reduce your costs and increase your income.

WINZ also have other special purpose benefits:-

Advance Payment Benefits

Recoverable Assistance Payments

Special Needs Grants

Domestic Purposes Benefits

But the applicability of these depends on each individual case and would need to be discussed with your Case Officer at WINZ

3. The local DHB will through its “in house” specialists (e.g. Physios and O.T’s) provide immediate physical assistance and Aids) to help get back into a home environment – but this is time limited.

DHB’s also provide through Disability Support Services –DSS – (directly themselves or a contracted “Provider”) an equivalent support for those over 65 with an “age related” disability to that provided through the Ministry of Health Disability Support Services for under 65 year olds -.subject to an Assessment

4. Ministry of Health – Disability Support Services

The provision of physical support:-

Home Support Services (usually requires a WINZ provided Community Service Card to qualify)

Respite care/Carer Support

Housing Modification/Equipment

for cases of physical disability **not** covered by ACC which is likely to result in an inability to live independently (i.e. carry out every day activities safely on your own) without support for at least 6 months. The Usual NZ residency requirements apply and generally only available for those under 65.

The first port of call is to Disability Information and Advisory Services (DIAS) to establish eligibility and to set up a Needs Assessment and Services Co-ordination (NASC) facilitator visit. They can firstly establish eligibility and then carry out and interview and assessment to establish what you can and cannot do and what help is already available to you. This can be set up whilst you are still in Hospital via the Social Worker allocated to your Ward. Your GP can also initiate a NASC.

This process can sometimes seem a bit invasive but it is important to set out just how difficult you are finding things. (see CCS help in 6 below).

Once an Assessment is made – and the type of help you need determined one of the contracted providers to DSS will make contact and initiate the service (see 5 below).

Once you are ready to think about trying to get back to work DSS can also provide a Work Place Assessment and work with your (willing) employer to set up your work station to make it easier to do your normal job. The Ministry of Social Development's Workbridge project assists similarly in this respect.

5. Support Service Providers

Access based in Wellington and **Enable N.Z** who are based in Palmerston North both operate throughout NZ but there are other “local” providers as well. Here in Nelson we also have Support Works who are part of the Nelson Marlborough DHB and cover the Top of the South island. You can make an application directly to such organizations although they usually respond to a request via Hospital Occupational Therapists and Physiotherapists following an assessment. Funded by the Ministry of Health these organizations are there to provide personal and home help and support together with the provision of wheelchairs, walking frames, canes etc. Additionally they can assist with motor vehicle modifications and home modifications (handrails, door widening, ramps etc.).

Note: Home modifications up to a limit of \$7500 can be approved before a means test is applied. Home modifications usually become the property of the home owner. The main problem is their limited funding so waiting lists are long (9 months for Housing mods unless “essential”) although short term “loans of equipment are possible to deal with urgent needs and all Hospitals are allocated local” funding to deal with urgent needs.. Equipment is provided on a loan basis until no longer needed and its aim is to “maintain or improve function”

6 Voluntary Organisations e.g. CCS Disability Action

CCS essentially act in an advocacy role for their clients – ensuring that the most appropriate services and assistance are in place. They also are contracted to (MoH) to provide specific services such as Wheelchair assessments and review of residential facilities and needs – but this may vary from region to region. They are also able to arrange provision of the orange disability stickers for your car.

CCS is probably one of the best places to make first contact with if you are located close to one of their centers or via their website as they will be able to point you in the best direction to get assistance.

CCS can assist with “coaching” for clients about to undergo a NASC

Other assistance that may be available in certain areas are:-

Driving Miss Daisy - - reduced cost taxis and transfer facilities

Super Grans—retired ladies who come round and help get domestic arrangements sorted after a hospital stay.

7. Charitable Organisations – There are some charitable organizations that do fund individual situations however they are few and far between and it has to be said that the likelihood of their funding a GBS'er is poor. Having said that if the residuals of GBS are severe and permanent it may be worth a trawl through the possible sources.

ADVOCACY:

If you experience problems with accessing a service or feel you are not getting the help and support you need the Health and Disability Advocacy Services is there to help resolve your issues and problems. Local Advocates exist throughout New Zealand and can be found in the local phone book or by e mailing

advocacy@hdc.org.nz

They operate under the auspices of the Health and Disability Commissioner.

CONTACT DETAILS

WINZ : www.workandincome.govt.nz

Ministry of Health – Disability Support Services. www.moh.govt.nz/disability

Local offices in most main areas under local names – e.g. in Nelson its “Support Works” in Auckland “Taikura Trust”.

CCS Disability Action: www.ccsdisabilityaction.org.nz

Disability Information Centres: www.weka.net.nz

Access www.access.org.nz

Enable www.enable.co.nz

Disclaimer

The information included in this guide is aimed at giving GBS/CIDP patients and their supporters an overview of the financial and physical help that may be available under national and local support scheme. It does not purport to be authoritative nor completely comprehensive and each person's circumstances will have an impact of the level of assistance they ultimately receive.

However we hope that it will ease the often confusing path to getting financial and physical help when GBS strikes.

A.R.Pearson

Secretary

GBS Support Group

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