MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Senate Community Affairs References Committee inquiry into the Purpose, intent and adequacy of the Disability Support Pension

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Introduction

MS Australia (MSA) is pleased to provide a submission to the Senate Community Affairs References Committee inquiry into the Purpose, intent and adequacy of the Disability Support Pension.

The focus of the comments provided in this submission are on key areas that will impact on people affected by multiple sclerosis (MS) and other neurological conditions for which our state organisations provide services and support. The comments have been provided by representatives of our state organisations who assist people to navigate the Disability Support Pension and, in some instances, directly from people living with MS. MS Australia's role is to work on behalf of our state and territory-based member organisations to provide a voice for people living with MS across the country.

MS Australia's member organisations are:

- MSWA (providing services and support in Western Australia)
- MS SA/NT (providing services and support in South Australia and the Northern Territory)
- MS QLD (providing services and support in Queensland)
- MSL (Multiple Sclerosis Limited providing services and support in Victoria, NSW, ACT and Tasmania)

Each of these state-based organisations operates independently to provide a range of services to people living with multiple sclerosis regardless of age, and, in some cases, to a broader group of people with other progressive neurological diseases. These services vary from state to state and include: phone information support and advice, on-line resources, MS clinics, specialist MS nursing, physiotherapy, allied health services, education and information workshops, seminars and webinars, psychology, financial support, supported accommodation, residential and in home respite, peer support co-ordination and employment services.

Summary of recommendations

MS Australia recommends that those meeting the eligibility criteria of DSP not be sentenced to further financial hardship and economic insecurity as a result of these inadequate payments and that the rate of DSP be raised.

MS Australia recommends that the word 'fully' be removed from the assessment criteria when determining if the condition is diagnosed, treated and stabilised.

MS Australia recommends that the process of achieving medical evidence is streamlined and demystified for both people applying and for those health professionals trying to support the application process and that the eligibility process of DSP does not generate further financial hardship and economic insecurity.

MS Australia recommends that to ensure people with MS with a disability have access to the DSP, where they do not meet 20 points under one impairment table, they are considered to meet the threshold across the impairment tables.

MS Australia recommends that the Program of Support be abolished.

MS Australia recommends that DSP information be provided in a range of formats, grounded in the principles of health literacy. Increasing a focus on individual and systemic capacity building within the sector, employing easy English and principles associated with health literacy principles will make marked improvements to current consumer interface issues.

The purpose of the DSP – a human rights perspective

The DSP, in essence, is a Centrelink payment that is means tested and provides financial support to people who have a physical, intellectual, or psychiatric impairment, either due to ill health or as a result of living with a chronic condition or disability, who have a demonstrated a continuing inability to work. Australians have provided some form of ‘pension’ or ‘benefit’ to people living with a disability since 1908.

The policy intent rests on the premise that as a country, we strive to protect and promote the economic and social wellbeing of our citizens. This is based on the principles of equal rights, equal opportunity and the public responsibility for citizens that are unable to avail themselves of minimal provisions for themselves or their family in circumstances that are out of their control (as set out in Article 25 of the UN’s Universal Declaration of Human Rights[1]). These rights were particularly hard fought by and for those living with the day to day impacts of disability.

MS Australia notes that, as a signatory to the UN Convention on the Rights of Persons with Disabilities[2], Australia recognises the need to enable persons with disabilities to live independently and participate fully in all aspects of life (Article 9) and that it is an equal right of all persons with disabilities to live in the community, with choices equal to others, and agreed to take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community (Article 19).

The Australian Government cemented this ethos through its National Disability Strategy 2010-2020 that is currently under review[3]. The Strategy provides a unified, national approach and commitment that acknowledges the need for policy and program development that aims to improve the lives of people with disabilities, their families and carers, and to provide leadership in the need to shift attitudes and to become a more inclusive country where each individual can fulfill their potential. Work towards the new strategy is ongoing.

According to the World Health Organisation, people with disabilities are the world’s largest minority[4]. Around 15 per cent of the world’s population, or estimated 1 billion people, live with disabilities. In Australia, over 4.4 million people live with some form of disability (of a total population size of 25.36 million in 2019), approximately one in five

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[1] https://www.un.org/en/about-us/universal-declaration-of-human-rights

[2] https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

[3] https://www.dss.gov.au/disability-and-carers/a-new-national-disability-strategy

[4] https://www.who.int/teams/noncommunicable-diseases/sensory-functions-disability-and-rehabilitation/world-report-on-disability

people[5]. Only 4.1% of the Australian population aged 16–64 is in receipt of DSP[6]. Only about 450,000 are participants of the NDIS[7].

Understanding MS

MS is the leading cause of disability in young adults. There are over 25,600 people living with multiple sclerosis (MS) in Australia. Most people are diagnosed with MS between the ages of 20-40, but it can affect younger and older people too. Roughly three times as many women have MS as men. Often a diagnosis of MS occurs when people are fully employed, planning a family and making significant career choices.

There are three courses MS can take. Around 15% of the MS population is diagnosed with a progressive form of MS with no periods of remission, termed Primary Progressive MS (PPMS). How fast the disease progress may vary, but the declining neurological progression is constant. Relapsing-remitting MS (RRMS), the most common form of MS, is characterised by partial or total recovery after attacks (also called exacerbations, relapses, or flares). 70 to 75% of people with MS initially begin with a relapsing-remitting course. Secondary progressive MS (SPMS) is a relapsing-remitting course which later becomes steadily progressive. Attacks and partial recoveries may continue to occur. Of the 70-75% who start with relapsing-remitting disease, more than 50% will develop SPMS within 10 years; 90% within 25 years.

There are no medications to cure MS, rather they are used to modify the course of the disease. 64%-79% of people with MS in Australia are using a disease modifying therapy (drug treatments designed to reduce the number and severity of relapses and slow or halt the progression of their MS). These treatments have made a dramatic difference in the lives of people with MS. For others living with progressive MS types, the availability of treatment options are more limited.

Although MS Australia represents a very small part of people in need of DSP, for those effected by the current DSP process, the impacts are profound. DSP is seen the last resort, a sober point of facing up to the irreversible impacts of MS - and not something anyone wish upon for themselves or their families.

> *"If you're lucky enough to qualify for the pension, I qualified on my second application, the financial support is inadequate. Living expenses continue to increase, but the pension doesn't."*
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> *"Lack of funds can be very isolating. You are unable to join friends on outings whether that be to dinner, the cinema or even going for a walk."*

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[5] https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/2018

[6] https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia-2020-in-brief/contents/income

[7] NDIA Quarterly report: 2020-21 Q3

Impact of MS on day-today life including employment

Some people with disability, including those living with MS, face day to day challenges to actively participating in everyday life. 32% of adults with a disability experience high/very high levels of psychological distress compared to only 8% of those living without a disability[8]. Over 50% of people living with MS will experience a major depression at some point in their lives[9]. While people with other chronic disorders also have high rates of depression, the rate is higher among people with chronic disorders — such as MS — that are inflammatory in nature.

The symptoms of MS can be both visible and invisible to others, are unpredictable and vary from person to person and from time to time in the same person. On average, in 2017, the quality of life of people with MS in Australia is 31% less than that of the overall Australian population. Quality of life for people with MS who are living with severe disability is 41% lower compared to people with MS with no disability[10].

An MS diagnosis has a significant impact on participating in paid employment. The employment of carers is also impacted. Over 64% of people living with MS stated that MS has an effect on their employment and their ability to earn an income. 69% of carers reported that caring has an impact on their own employment, family and relationships[11].

Given that MS is a progressive, degenerative, neurological condition, where acquisition of disability often occurs gradually, a major focus for MS employment services is supporting people with MS to remain in employment for as long as possible[12].

In Australia, five out of ten working-age people with disability (48% or 984,000) have a lower employment rate than 8 out of 10 people living without disability (80% or 11.3 million)[13].

MS Australia believes that if someone has a disability or a chronic condition, such as MS, that prevents them from gaining or maintaining sufficient paid work, they should have access to the DSP. There is no basis for denying people in this position access to DSP when their ability to seek, get, and maintain sufficient paid work is constrained by their condition.

"The DSP is very inadequate. Bad enough having a disability and being stressed over symptoms as well as financial expenses going up! Very much way below poverty line if I could work I would but my MS won't let me!"

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[8] https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia-2020-in-brief/contents/income

[9] https://www.msaustralia.org.au/living-with-ms/expert-blog/multiple-sclerosis-and-depression-%E2%80%93-it-seriously-complicated

[10] https://msra.org.au/wp-content/uploads/2018/08/executive-summary_health-economic-impact-of-ms-in-australia-in-2017-report_ms-research-australia.pdf

[11] https://www.msaustralia.org.au/news-blogs/latest-news/meeting-needs-people-living-ms-their-families-and-carers

[12] https://www.msaustralia.org.au/ms-employment-support-service-ess-team

[13] https://www.aihw.gov.au/reports/disability/people-with-disability-in australia/contents/employment/employment-rate-and-type

Financial burden of living with a chronic condition

One in six people with a disability lives in poverty according to an ACOSS/UNSW report in 2018[14]. These numbers are likely to be under-estimations as the report did not adjust for additional costs resulting from living with a disability day to day i.e. modifications at home, personal support and care, medical and pharmaceutical expenses and additional transport costs.

Although there are safety nets, such as the DSP and some people living with disability do maintain some level of employment, "people with disability generally have a lower level of personal income than people without disability. Having a person with disability living in the household is also associated with lower levels of household income." They are also more likely to experience poor health, discrimination and violence than those without disability.

MS Australia, with a number of other peak bodies, believes that the DSP, in it current state, is not meeting its purpose in supporting people with a disability, their family and carers, to live independently, safely and have equal access and rights to participate in the community.

Living in poverty impacts on all areas of life, particularly a deterioration of mental health, lack of social inclusion, connection, and loneliness. Over 70 studies have found that loneliness rivals the risks of obesity, smoking and air pollution and that lonely people are likely to die prematurely than those living with healthy social connections.

DSP levels are not adequate for those eligible and successful in claiming DSP. In 2017, the average cost of MS per person was $68,382 (comprising both individual and societal costs.) - similar to that of someone with Parkinson's disease or the first year after a stroke, triple that of a person with type 2 diabetes. The societal and individual burden of disease for MS, in comparison to other disease and disability types are high. For those lucky enough to qualify for DSP, the feedback was clear that the support does not meet the day to day living expenses for someone living with ill health, a chronic condition or a disability associated with multiple sclerosis. More worrying, those unable to meet the eligibility criteria of DSP have to survive on other benefit types which have already been criticised broadly for being inadequate for those living with full health.

> *"Whilst I'm extremely grateful for the DSP – it is my only source of income – it doesn't cover a lot of my expenses. Essentially bills, food and medication are just covered but with rising food costs it is becoming much more difficult. There is no leeway for emergencies or any extras. I used to take VitD supplements but can no longer afford them. Lack of funds can be very isolating. You are unable to join friends on outings whether that be to dinner, the cinema or even going for a walk."*

MS Australia recommends that those meeting the eligibility criteria of DSP not be sentenced to further financial hardship and economic insecurity as a result of these inadequate payments and that the rate of DSP be raised.

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[14] https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia/contents/employment/employment-rate-and-type

DSP application process

Widely published reports of DSS demographic data, indicate that receipt of the DSP has been declining over time, largely because of changes to eligibility criteria that have reduced the number of people successfully claiming the payment.

Feedback from applicants diagnosed with MS indicates that, even if successful, they will have their claim rejected several times; they are often exasperated by the application process which takes a considerable psychological toll.

Published reports and anecdotal feedback indicates that:

- **The application process for DSP is too complex**[15,16,17]. Despite the necessity of the DSP for those unable to work due to their increasing disability and functional impairments, successful applications are notoriously hard to achieve. Many applicants are simply overwhelmed by what is required of them.

- **The application process for DSP takes too long[18]**. An average claim can take anything from 6-18 months to complete.

- **During this process time, applicants receive a lower payment** which is totally inadequate even for those living without the burden of a disability[19], sentencing people with disabilities and their carers and children to a life of poverty – removing their choices, rights and inclusion.

> *"It's a long slow process that if you don't get the wording right you won't get it the first, second or third time you apply for it."*

Difficulties experienced by people living with MS navigating the DSP application process are set out in the two case studies below.

Two case studies:

Mandy Hunwick used to love going to work, but then it all became too stressful.

Her vision became blurry, she couldn't remember simple tasks and became increasingly fatigued.

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[15] https://www.nssrn.org.au/advantages-of-having-a-lawyer-handle-social-security-disability-cases/

[16] https://www.ejaustralia.org.au/wp/social-security-rights-review/disability-support-pension-fresh-pro-bono-lawyer-insights-from-hall-and-wilcox-volunteers/

[17] https://www.papergiant.net/projects/dsp-help

[18] Social Security Rights Victoria https://papergiant.net/work/dsp-help

[19] https://www.abc.net.au/news/2019-09-12/disability-support-pension-applicants-diverted-to-newstart/11486164

The 42-year-old was eventually diagnosed with Multiple Sclerosis (MS), along with auto-immune arthritis and vasculitis, a disease that restricts blood flow.

Ms Hunwick was forced to leave her job at a Queensland government department and applied for the Disability Support Pension (DSP).

"I thought that it was going to be a short, easy process," she said.

"It took 17 months. And I had to fight for it. I literally went through hell just trying to get it. And it caused me to almost want to kill myself," she said.

She applied for the DSP in January 2018, providing Centrelink with statements from doctors and occupational therapists.

Eight months later, she was rejected. She applied for a Centrelink review and her application was turned down again.

"To be told you're not disabled enough when you can barely get out of bed some days, you can't understand how somebody can judge you that way," she said.

While applying for the DSP, Ms Hunwick received a Newstart allowance but a medical exemption meant she didn't have to search for a job.

Ms Hunwick is one of a record number of people with disabilities being put on Newstart payments, with Centrelink having denied their applications for the more generous disability support pension.

Ms Hunwick's application was overturned by the Administrative Appeals Tribunal in June 2019, which effectively ordered Centrelink to approve her for the DSP.

"Why would you want to make it so hard for somebody who's already living such a hard life?" she said.

Rachel Park knows all about those additional costs, after being diagnosed with an aggressive form of MS in 2017.

Her symptoms include severe fatigue, muscle pain, blurry vision, memory loss and partial paralysis on the left side of her body.

Like Ms Hunwick, the 24-year-old also thought it would be straightforward when she submitted her DSP application to Centrelink.

"I kind of assumed that they were going to be medical professionals. But they are not," she said.

Her application was rejected last spring and she was put on Newstart.

"I have to go see Disability Employment Services every fortnight and I have to do a job plan and apply for a certain amount of jobs per month," she said.

To meet her Newstart requirements, she sends online inquiries to employers and said she rarely gets a response.

Ms Park said her neurologist and doctor advised her not to work.

"When it comes to MS, you really just have to focus on your health... if I get too emotional one day, or I'm too stressed, my left side dies and I'll be limping around," she said.

For Ms Park, receiving Newstart instead of the DSP has had a big impact, and she's now moved back to Brisbane from Sydney to live with her parents.

Her additional expenses including medicine, specialist appointments and therapy to slow her muscle wastage, which can add up to $500 per month.

"[The DSP] would be a huge difference because I wouldn't have to rely so much on my parents," she said.

"Just getting the little money on Newstart, it just makes your life so much harder."

Excerpt from ABC article 'Record number of people with a disability being forced onto Newstart' By national social affairs reporter Norman Hermant
Posted Thursday 12 September 2019 at 4:58am, updated Thursday 12 September 2019 at 8:06am. See full article here: https://www.abc.net.au/news/2019-09-12/disability-support-pension-applicants-diverted-to-newstart/11486164

Medical eligibility

Medical eligibility is currently based on evidencing how a condition or disability affects a person's ability and capacity to work. To meet the eligibility criteria, applicants must demonstrate that they have a 'fully diagnosed, treated and stabilised condition'. For a condition to be accepted as ***fully** diagnosed*, the diagnosis must be made by a qualified medical practitioner. Most people with MS are diagnosed by a specialist MS Neurologist.

DSP applications, however, require supporting evidence from other treating health professionals to evidence if the condition is *fully treated* or if 'reasonable treatment or rehabilitation has occurred'. The assessment considers the success rate, where "substantial improvements are expected, the effectiveness of past treatments and any plans of future treatments, including the duration of waiting lists". A condition should also satisfy the criteria of being '*fully stabilised'*. Other than a six-page, small print explanatory *Medical Evidence Checklist* for treating health professional (SA478) there are no proformas to guide health professionals to support and meet these requirements.

MS Australia believes that these criteria are often misunderstood by people assessing claims, leading to rejection of claims even though the person's condition will not change. The complexity and unpredictability of MS does not align with 'fully diagnosed, fully treated and fully stabilised'. Having a progressive, degenerative, episodic, chronic and often "invisible" disease should not make people ineligible to apply for the DSP.

MS Australia recommends that the word 'fully' be removed from the assessment criteria when determining if the condition is diagnosed, treated and stabilised.

Cost of providing medical evidence

A medical professional can only recoup payment for the provision of these medical evidence from DSP if they are engaged by Centrelink. Otherwise the financial burden is carried by the person applying. Additionally, the financial and organisational burden to obtain and secure the relevant medical evidence to meet the DSP impairment and qualification requirements rest with the applicant.

For those residing **in rural and remote locations**, obtaining the necessary evidence from specialists can come at even higher financial cost. Without the specialist medical reports, the success of meeting the medical eligibility will be based on the opinion of the job capacity assessor or Government Contracted Doctor on the basis of available evidence. But, an opinion will only be given if the medical condition has been fully diagnosed, treated and stabilised, based on primary medical evidence already provided[20].

<u>MS Australia recommends</u> that the process of achieving medical evidence is streamlined and demystified for both people applying and for those health professionals trying to support the application process and that the eligibility process of DSP does not generate further financial hardship and economic insecurity.

If an applicant can satisfy the above, assessment will commence to determine the functional impacts against the **15 Impairment Tables**.

Impairment Tables

To meet the DSP requirements, an applicant needs to have either an impairment rating of 20 points or more on a single Impairment Table or 20 points or more in total from across more than one Impairment Table and meet the Program of Support rules. (Zero points suggest no functional impairment and 30 points suggest extreme functional impairment.)

To meet the 20 points, additional to the medical evidence required, applicants are also required to attend a Job Capacity Assessment, conducted by job capacity assessors, and a Disability Medical Assessment provided by a government-contracted doctor to satisfy their impairment and continuing inability to work requirement.

Meeting the requirements of the impairment tables is often confusing for applicants and medical practitioners alike. Successful applications are dependent on the provision of very specific medical evidence, with little guidance to clarify what exactly is required.

People with MS sometimes live with a range of comorbidities. DSP eligibility criteria should recognise the impact of multiple disabilities or illnesses across multiple impairment tables on someone’s capacity. The requirement for people who score less than 20 points against one impairment table to engage in a Program of Support to qualify for DSP results in situations whereby clearly incapacitated people are required to engage in employment services despite having very limited ability to engage at all!

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[20] https://guides.dss.gov.au/guide-social-security-law/3/6/2/10

It is important that an individual's overall incapacity is understood in the DSP claim process, and not hampered by relatively arbitrary rules within the assessment tables themselves.

<u>MS Australia recommends</u> that to ensure people with MS with a disability have access to the DSP, where they do not meet 20 points under one impairment table, they are considered to meet the threshold across the impairment tables.

This process is further complicated by the fact that health care professionals and specialists often do not have time to complete complex and lengthy medical reports or letters.

Finally, after providing evidence that 1) their condition is fully diagnosed, treated and stabilised and 2) that they are meeting the requirements of the impairment tables, the applicant has to satisfy that they have actively participated in the Program of Support.

Program of Support

The **Program of Support** [21]is required for those 'not manifestly medically eligible' and 'their condition attracts a total of at least 20 points under the Impairment Tables'. Applicants must show they are actively participating in this program *for at least 18 months in the 3 years before their claim.*

The DSP applicant has to attend a designated Program of Support Provider, who would provide them with vocational, rehabilitation or employment services with a particular focus on developing skills the person requires to improve the person's capacity to prepare for, find, gain or maintain work. "Any periods during which a person who started a POS does not participate in it for any reason (including when they are exempted on medical or any other grounds, are suspended from the program or are in the period of relief from the program) do not count as participation in a POS" (DSS Guide 1.1.A.30). This is particularly problematic for people with MS who live with unpredictable and episodic changes to their symptoms and functional capacity, often causing further delays in their application process.

The Program of Support in its essence deters successful DSP applications – creating hurdle after hurdle - unnecessarily prolonging the time to complete an application for DSP. The Program of Support, especially and specifically, is causing many people, including those living with MS, to miss out.

<u>MS Australia recommends</u> that the Program of Support be abolished.

Finally, after 1) a person meets the medical evidence criteria, 2) the impairment tables rating and 3) has successfully completed the program of support criteria, the next hurdle is to proove that they have a **continuing inability to work.** According to Centrelink advice, an applicant meet this requirement after medical evidence demonstrate that the person is 'unable to work, or be retrained for work, within the

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[21] https://guides.dss.gov.au/guide-social-security-law/1/1/a/30

next 2 years because of impairment'. For the purpose of assessment, 'work 'includes at least 15 hours per week at or above the minimum wage and if the work exists in Australia, "even if not within the person's locally accessible labour market" - 15 hours work per week is a sentence to poverty!

Improving communication

From our feedback sought from our members and the MS community, it was also evident that improvements are needed in the way the **DSP program communicates its process of application and decisions to applicants** and those seeking to support applicants in the process. Our MS community often does not fully understand what information they have missed, what further evidence do they need to provide or how they can ensure their evidence meets the requirements of the application process – because this is not adequately communicated to them.

DSP information should include what the DSP is; how to apply; proformas and templates for all conditions and clear guidance on why an application was not successful and what can be done to improve future applications. Communications that enable individual and systemic capacity building.

> *"I was recently rejected for DSP. I've had MS for over 10years now. I've had to change my whole way of living because I did not qualify. First I lost my job…and way of earning any $$$ because of COVID-19. Then I got rejected for DSP. Heart breaking. The whole process of the pension application was extremely slow & in the end after my assessment what it came down to was a phone call interview to determine the final result."*

<u>MS Australia recommends</u> that DSP information be provided in a range of formats, grounded in the principles of health literacy. Increasing a focus on individual and systemic capacity building within the sector, employing easy English and principles associated with health literacy principles will make marked improvements to current consumer interface issues.

Conclusion

As a country, we strive to protect and promote the economic and social wellbeing of our citizens. This is based on the principles of equal rights, opportunity and the public responsibility for citizens that are unable to avail themselves of minimal provisions for themselves or their family in circumstances out of their control (Article 25 of The International Bill of Human Rights). Rights that were particularly hard fought by and for those living with the day to day impacts of disability.

The Disability Support Pension (DSP) forms a critical part of our income support system but unfortunately, over the years governments have made changes to limit access to the payment to reduce overall social security spending. People with MS whose impairments significantly limit their prospects of entering or remaining in the workforce are denied DSP, and many spend considerable time and resources appealing denied application decisions, often without understanding why their application was denied.

The costs of disability arising from a chronic condition like MS are not sufficiently reflected in the rate of the DSP, meaning that long-term recipients with disability can face abject poverty.

The DSP application process speaks of mistrust, red tape and confronting people with disabilities with many obstacles, hurdles and barriers resulting in many people just giving up.

This submission highlights a number of key weaknesses in the DSP system and makes recommendations to ensure the DSP is available to people who need it, and provides sufficient support when they receive it.

KEY FACTS ABOUT MS:

- Multiple sclerosis (MS) is a neurological condition affecting the central nervous system (brain and spinal cord) that affects more than 25,600 people throughout Australia
- It is the most common chronic neurological condition diagnosed in young adults.
- MS is most commonly diagnosed between the ages of 20 and 40
- 75% of people diagnosed are women.
- MS varies significantly from person to person. For some people, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others it means a progressive decline over time. For all, it is life changing.
- Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems.