

Benefits Advice Service for People with Multiple Sclerosis

- Delivered by Disability Sheffield and Citizens Advice Sheffield
- Funded by Rotherham and Sheffield MS Society Branch

1. Background

In early 2017 discussions took place between Rotherham and Sheffield MS Society, Disability Sheffield to develop a specialist, independent, confidential and impartial advice service providing advice on state and local authority benefits to people with MS, their carers and families.

The service was to be easily accessible via a dedicated phone line and email address through which people with MS could refer themselves or be referred by family, friends and health professionals.

The purpose of the service was to simplify and standardise the availability of help and advice with all aspects of the benefits system from initial assessment of eligibility through completion of application forms to appealing decisions

The service would be promoted and advertised via the specialist MS nursing service, the MS Society therapy centre and others.

2. The Client Group

People who develop multiple sclerosis and other permanent and incurable conditions at some point in their lives can be seen as a distinct group of disabled people with their own difficulties and needs.

- MS is incurable and treatment is limited and damage caused by it is irreversible. There is no operation, procedure or cure.
- Its progress and symptoms vary from case to case and are largely unpredictable. Many of the symptoms are not immediate or obvious.
- For example, fatigue, which is one of the symptoms often reported by MS patients as being the most disabling, is not always felt immediately after doing a task or activity but can be so severe the next day that the person literally does not have the energy to get out of bed.

- These aspects of MS are not widely appreciated and cause particular difficulty for people with MS in successfully applying for benefits, which is very much geared towards conditions which have symptoms which are consistent, clear and immediate. In particular the DWP do not always appear to realise that the term 'relapsing and remitting' does not mean that the effects of the condition are sometimes not felt at all or if so, only mildly. People with MS are often say that they are significantly affected all of the time but during a 'relapse' it is even worse.
- People with MS, therefore in addition to having to come to terms with having a condition which will never improve and will probably get worse and which will affect them in most aspects of their lives, have to cope with a benefits system which can be confusing and frightening to anyone, but which in some respects is even more difficult for them to qualify for than people with some other long term conditions and disabilities. This emphasises the need for an advice service specifically tailored to their needs.

3. The Service

It was agreed from the outset that the service would be available to all people diagnosed with MS and their carers and immediate family within the catchment area, comprising:

- Sheffield
- Rotherham

The Rotherham and Sheffield MS Society Branch funded the service initially for a one year period, this was extended for a further 9 months. A partnership was formed with Citizens Advice Sheffield in order to deliver the service, recognising their benefits expertise particularly in supporting people at appeal tribunals. Both organisations provided a benefits advisor 1 day per week to provide the service, based in Disability Sheffield's offices.

Originally, in addition to this, people with MS living in Barnsley were also invited to contact the service via Disability Sheffield who would make a referral for them to DIAL Barnsley who would give them an appointment at their monthly Friday drop-in. this funded by the Barnsley branch MS Society.

Unfortunately, it soon became clear that the number of people living in Barnsley needing the service significantly exceeded the capacity of DIAL's drop-in (3 – 4 appointments per month). This was exacerbated further by the large proportion of these clients who were, due to their limited mobility, unable to travel to DIAL Barnsley's premises and so required a home visit. The travelling time involved to provide this had to come out of the time available to see clients effectively reducing the number of people DIAL could see in each monthly session to only two.

This was particularly difficult for clients facing deadlines for returning benefits forms or challenging decisions.

Also, DIAL did not have the capacity to represent clients at appeals, which the rest of the service could. This meant that MS clients living in Barnsley could potentially receive a slower and less comprehensive service than those living in Sheffield and Rotherham.

In 2018 therefore, it was decided that people with MS living in Barnsley would simply be signposted to DIAL Barnsley or Barnsley Citizens Advice.

Also, in mid-2018 the service held three drop-in sessions at the MS Therapy Centre in Catcliffe, staffed by both the Disability Sheffield and CAB advisers. These were advertised by the centre beforehand and were well attended with between four and six people seen at each session.

4. Scope

All aspects of UK state and local benefits were covered by the service, including;

- Employment Support Allowance
- Personal Independence Payment
- Disability Living Allowance
- Universal credit (introduced for Sheffield claimants in November)
- Housing Benefit
- Council Tax Support

A particularly common issue during this period, which is continuing, was the transfer of claimants receiving Disability Living Allowance on to Personal Independence Payment. This is an issue which causes claimants extreme anxiety particularly those with severe mobility issues who could potentially lose not only a significant amount of their income but also, if they have chosen to use their award of the higher rate of the DLA mobility component to hire a car under the Motability scheme, their main means of transport.

It was broadly agreed that the Disability Sheffield adviser would cover all stages of the process up to a decision being made on the claim. If the claimant was unhappy with the decision the adviser from Citizens Advice Sheffield would help with challenging the decision including, where possible, representing at appeal tribunals.

5. Impact and results

At the time of writing, a total of 154 clients had used the service, for help ranging from one-off queries to representation at benefit appeal tribunals. Of these, so far, 64 have received positive financial benefit in terms of benefit claimed for the first time, retained or increased, and other issues such as alleged overpayments of benefits written-off or reductions in financial contributions charged by Sheffield City Council towards the cost of care packages.

There were also non-financial gains such as applications for disabled parking 'blue' badges and disabled persons 'free' public transport passes. There were also several cases of checking that a client was receiving all of the benefits they were entitled to. Even when it was confirmed that this was the case and would not lead to further income, this provided the client with reassurance that their benefits were correct.

So far a total of £5934.19 per week (equating to £313765.28 annually) has been achieved for clients. In addition a further £1228.00 per week (£63856.00 annually) has been gained through successful benefit appeals and mandatory reconsiderations. There are still several benefits claims we have helped with which have not yet received a decision and several appeals which have been lodged but not yet heard (the current waiting time for appeals to be heard in Sheffield is between nine and 12 months). Therefore it is likely that these figures will increase further.

In addition to these quantifiable benefits of using our service clients have expressed their appreciation of the following:

- Simplicity of obtaining help via a dedicated phone line.
- Speed of response (there has never been a waiting list for this service and most clients have been able to get an appointment within one to two weeks of their initial contact).
- Feeling that they receive a personalised, one to one service from advisers who demonstrate at least some understanding of their condition and its effects.
- Ability to see the client in their home where they are unable to travel due to mobility issues.
- Feeling that they have been listened to and not rushed.
- That they understand the system better, even when they are not entitled to a particular benefit.
- That they receive 'one stop' holistic support with the entire process. In particular many clients have stated that having someone go with them to face-to-face assessments and appeals has been of real value and encouraged them to put their case more effectively.
- In summary, they are very grateful not to have to face the system alone.

These are reflected in feedback left by clients:

"A great job"

"I have found the help invaluable both for relieving the anxiety...and in the knowledge the adviser displayed"

I couldn't have filled in my PIP form without it"

(The adviser) “couldn’t do enough...(were) “in touch frequently and I felt reassured every step of the way”

*(The adviser) “explained how to fill in the form and made things very clear”
“I was helped through an entanglement of new rules and regulations which I was not aware of” and “I was able to claim benefits which I wasn’t aware of”*

Clients also praised the “friendly and relaxing environment” and the “personal attention”, “friendly attitude with no judgement” and “knowledgeable and sympathetic attitude” of the advisers.

The one comment which best sums up the benefit felt by most client, however, was
“I would recommend the service because of the advice workers’ understanding and expertise of the benefits system. It is a very stressful and daunting time”.

6. Case Studies

The following anonymised examples demonstrate the ways in which the service has helped people with MS to deal with very worrying and complex situations.

Mr Donald K

Donald was a middle-aged man who had worked full time in physically demanding jobs all of his life. He saw this as his main purpose and role.

After he was diagnosed with MS he kept on working as long as possible, but got to the point where even with considerable support from employers and Access to Work, he was forced to leave on medical advice, due to pain and exhaustion. He had never claimed anything in his life and did not know where to begin. He also felt ashamed and embarrassed about having to stop working and was reluctant to talk about his difficulties. With the service’s help, both completing forms and attending face to face assessments he was awarded Employment Support Allowance and both the Daily Living and Mobility components of PIP.

Mrs Carol A

Carol had been diagnosed with MS when only in her twenties and had received Disability Living Allowance at the highest rates of both the care and mobility components for many years, on what was then described as a “life time” award. She used the award of the DLA mobility component to hire a care under the Motability scheme. She found the car to be invaluable as it was her sole means getting outdoors and having a life outside her home. She was very scared that this car would be taken away from her because of the difference between the DLA and PIP mobility criteria.

With help throughout the process she maintained her entitlement to the maximum rates of both components.

7. Summary

The MS Benefits Advice Service has been a great success and valued and appreciated by its users. The reassurance and guidance through what many find to be a frightening and bewildering system often for the first time appear to have been as valued by the clients as the outcomes of their claims.

The closure of this service has come at a particularly unfortunate time. Since April 2019, the DWP has contacted a large number of people in the Sheffield area advising them that their DLA claim is ending and inviting them to claim PIP instead. We have been contacted by six people with MS in May and June 2019 after receiving these letters asking for help with this. Already anxious at the thought of losing some or all of their benefit, they now have to rely on an already busy Citizens Advice service which cannot always provide the same speed and flexibility. Some of these people have been recommended by previous users of our service and have expressed anxiety and disappointment about it no longer being available.

Also, the introduction of Universal Credit for new claimants living in Sheffield in November/December 2018 has added to the complexity, uncertainty of the process. People with MS having to give up paid work and claim income replacement benefits now have to navigate an even more complex system under which some people are likely to be worse off. The full impact of this is yet to be felt.

Therefore, demand for a specialist personalised, flexible, holistic benefits advice service for people with MS, their families and carers will continue – and possibly increase - for the foreseeable future.

Disability Sheffield MS Benefits Advice Service monitoring information			
Outcomes for the life of the project - 1st August 2017 to 20th April 2019 (21 months)			
Client information	No. of clients:	Total	% of total
	New clients	154	
	Returning clients	-	
	Ongoing cases (as at 30/04/19)	10	
	Total no. supported	154	
	Client type:		
	Person affected by MS	145	94
	Carer of person with MS	9	6
Where the client heard about the service	Health professional (including MS Nurses)	126	80
	Advice service	8	5
	MS society branch	5	3
	Self/relative	5	3
	Other – DS / MP	14	9
Service provided (individuals may be double counted where they have received advice/support relating to more than one)	Service		
	Benefits - PIP	90	55
	Benefits - DLA	1	0.5
	Benefits - ESA	24	15
	Benefits - CA	1	0.5
	Benefits - tax credits	1	0.5
	Benefits - HB	3	2
	Benefits - other	27	16
	Benefits - non-income (bus pass, blue badge)	7	4
	Appeals	7	4
	Debt/other financial issues – contribution to care costs	4	2.5
Outcomes			
Income generated	No. of clients where income was generated due to benefit claims	61	95
	No. of clients where debt was avoided/managed	3	5
	Total clients - income was generated or debt avoided	64	100
	Amount due to benefit claims (weekly)	£5934.19	
	Amount due to benefit claims (annual)	£313765.28	
	Total amount of new income (weekly)	£5934.19	
	Number of clients with non-financial outcomes	31	
	Outcomes for non-financial issues:		
	Blue Badge	6	
Public transport Mobility Pass	4		
Benefits check/information	21		
	No. of successful appeals	12	

Outcomes of appeals	Amount of benefits claimed through successful appeals (weekly)	£1228.00	
Referrals to other services	Services referred to:		
	Advice service - other service	2	15
	Specialist employment advice	1	8
	Other organisation - DS Advocacy	10	77
Service management information			
Location of appointments	No. of clients seen at MS Therapy Centre	10	6
	No. of clients seen at advice service office	24	14
	No. of clients seen at home	38	23
	No. of clients seen at DS office	51	31
	No. of clients seen at Barnsley DIAL	13	8
	No. of clients advised by letter/email/phone	29	18
Waiting times for this service	Average waiting time for an office appointment		
	Average waiting for a home visit		
	Current waiting list (no. of people)		
	Current waiting time for an appointment		
Complaints	Number of complaints received during the quarter		
	No. of complaints resolved during the quarter		
	No. of complaints outstanding		

Notes: From Q3 (Feb-April 2018) figures for DIAL Barnsley were not included.