Information at the Point of Diagnosis

Cheshire/Mersey and North Wales

Service Improvement Forum

January 2022

Experts in MS

An introduction to Service Improvement Forums

In 2020 the MS Society launched a new service improvement programme to support professionals working in MS and neurology services to adopt new and innovative ways of working, and to embed improvements across service pathways and clinical commissioning groups (CCGs) / integrated care systems (ICS) structures.

Focussed on delivering one of our organisational goals - "**Ensuring everyone can access high quality treatment, care and support**"- our Stakeholder Engagement Team has worked at a local level with a range of professionals and people using MS services.

Given increasing demands on health and social care services, and competing priorities for staff time, the service improvement programme focuses on embedding change across systems to ensure it is sustainable. Through our Experts in MS we provide professionals with the resources they need to implement this change and a space to develop understanding and innovation.

The programme approach is twofold:

Proactive - identifying new and innovative ways of working; providing opportunities to evaluate and quantify the impact of new service models and pathways; showcasing these success stories via webinars, reports and forums to enable other professionals to adopt them

Reactive - engaging with local services and people to understand current unmet need and opportunities to improve; convening and facilitating action planning forums to affect change; providing evidence, templates and best practice example to enable change to happen

Our service improvement forums are therefore both national showcases of best practice and new effective ways of working, and local system improvement implementation mechanisms.

Both driven by evidence and the voice of our MS community

Contents

Summary

Background

This workshop is in response to the action plan put together from the Cheshire and Mersey MS pathway workshop that took place on the 4/11/20 – jointly organised by the MS Society with Walton Neurological Centre and Wilmington Healthcare.

The MS pathway workshop brought together people living with MS, health care staff and commissioners to discuss the optimum MS pathway and current gaps in delivery in the pathway in Cheshire and Merseyside.

The action plan identified the following two actions amongst others:

- 1.1.3 - Focus groups to support discussion that will focus on a simple check list that can be used to support people living with MS making a decision on which drug to take.
- 1.1.4 - Outline template for clinicians to use in consultations to ensure all identified issues are addressed

Need

The need identified came from discussions at the MS Pathway workshop in November 2020 where people living with MS stated that they didn't always find they could ask the questions they wanted to, and they wanted to see standard information being provided to enable people to access the services that were important to them.

This is also a response to the information gathered from MS Society focus groups that took place across England in October/ November 2019 which identified that people often don’t feel like partners in their treatment with one person saying -

> “Hold on this is my appointment not yours”

Recommendations/ Developing a Check List and wider service development needed

The discussion with the people who took part was wide ranging and drew out a number of specific points and questions. This will be discussed and developed in partnership with health care staff to produce a useful and manageable check list / questions and points that people living with MS would like to be addressed as they go through the journey of being diagnosed.

In addition to this there are wider issues that the discussions raised that need to be picked up on by services and health care more widely. The information below is therefore split into two sections.

- Suggestions for questions, and
- Points to be discussed and developed into a check list for health care staff. (Part of the work on this will be identifying with health care staff what is already offered and/ or available)

Development of a checklist

The people 'breaking the bad news' and providing information need to use all their sensitivity to find out how much the patient knows already. This may include:

- Age
- Work
- Education level
- Have they met anyone with MS?
- Have they read leaflets / what do they know from the websites and which websites they have been on.

The questions that people who took part have identified that they would like to have asked from point of diagnosis are:

- How much more do you want to know?
- What's your job? / How is your job going?

- What’s your home / family situation? Have you got people around you who can support you?
- What do you want to achieve? Is this a good time to talk?
- How much do you understand? How much have you been able to take in?

Having asked these questions people who took part identified the need for standard information categories. Having found out more about the patients they should point people in the direction of and/or give the relevant level of info.

- Ensuring people understand that they are not to blame for getting MS.
- Provide links to good information on the treatments available including information about eligibility in particular linked to the DMT’s for progressive MS.
- Access to emotional support at point of diagnosis as standard.
- Provide access to information / referral to services that can provide support with movement and exercise, emotional wellbeing and employment. Exercise and movement was mentioned many times in particular where someone could go that would be supportive/ have knowledge of MS and neurological conditions.
- This wider access to services needs to include local MS Support groups, therapy centres and where available access to social prescribing, wellbeing coaches and leisure services. This should also include referral to these services where that is possible.
- Providing information on trials and new and emerging drugs and therapies.
- The importance of providing this information in an easy to use way was emphasised when one person said (and several agreed) that if this isn’t provided then you seek it out on google:
- ‘Knowledge is power but you need to know how to use it. It can be unhelpful to google information - don’t want to feel bombarded with it.’ Several people agreed ‘This can make you feel scared.’

Addressing the wider Service Development Need identified by the above Discussion

In order to fully address the points raised by the people who met in the forum on the 30th November wider service development needs to take place. There was a workshop held on the 17th November that looked at ‘Access to therapies for people living with Neurological Conditions in Cheshire and Mersey.’

These wider discussions for the people living in Cheshire and Mersey include recommendations that would support meeting the needs identified above and included:

- The development of, and closer working between, physical and mental health services that provide therapeutic support to people living with long term and neurological conditions.

- Ensuring people living with MS had the information about the Nurse Advice Line. Information on the patient initiated follow up work in Walton was shared by the facilitator and this just made the need to share the Nurse Advice Line and access point for people using Walton’s services more important. Several people in the workshop were unaware of the advice line.

- The developments will be supported by actions taken forward from the Access to Therapies workshop that took place on the 17th.

- Ensure there is guidance, training and support for staff in breaking bad news.

- There were a number of people in the discussion group from North Wales and there will be a need to link these wider needs into the discussions and service development taking place in North Wales. This will include sharing the above points and discussions with service provider in North Wales and with Betsi Cadwaladr on the work they are currently undertaking in designing therapy led care.

Next steps

The next steps detailed below will be supported by an action plan and will be reported to the Cheshire and Mersey Neuro Science Programme Board where progress is being monitored.

- There is a detailed list of next steps at the end of this report that will support the development of a check list that will build on existing good practice, currently proposed as completed by the end of 2022.
- The actions and recommendations from the above mentioned 'Access to Therapies' workshop will also enable the points raised in the discussion below to be addressed and built into service delivery across Cheshire and Mersey, and it is hoped support service development in North Wales.

Methodology

The work to develop the check list will include:

- Gathering information from people living with MS on their experience of information provided at point of diagnosis and what they think they need to be asked and supported with when considering Disease Modifying Therapies (DMT's).
- Writing up the information from the above discussions and with a smaller working group - agreeing a manageable draft check list.
- Sharing this draft with participants and more importantly at this stage developing a discussion and agreement with health care staff to build on existing good practice and identify what is useful / manageable as a working check list.

Gaining approval for the use of this check-list from Walton Centre boards and also report through to the Neuro Science programme board to provide support for the wider service development identified below.

How was the discussion with people living with and affected by MS developed?

A small working group of people living with and affected by MS was set up with members drawn from the people who attended and expressed an interest in the pathway workshop.

Two members of that working group supported the development of the questions for this session (See appendix 1)

The forum was delivered online, and promoted via local groups, The Neuro-Therapy Centre (Chester), local Healthwatch groups and the Brain Charity.

At the session there was:

- A brief introduction on the background and purpose of the event and any questions on the process were answered.
- The 18 attendees then split into two groups and the questions in appendix one were discussed. In each group there was a facilitator and a scribe to record what was said.

- The groups briefly came back together at the end and shared two or three priority points they had discussed.

Detailed findings

The discussion enabled people to talk about their experiences of the services and information that were provided at point of diagnosis and linked to accessing treatments such as DMT's. This led to a discussion which focused on the gaps in the information given. The comments given below provide an opportunity to develop patient experience so the service provided links more closely with the goals and aspirations of people living with and affected by MS. It is important to acknowledge the valuable service provided that people identified in the discussion probably best summed up by the following comment from the discussions:

'X' was diagnosed at Preston and when they asked to be referred to Walton this was a revelation to them. They said even though elements of the service could improve they were extremely impressed with what they were offered. Specifically they referenced to the range of services available and the access to DMTs. In addition to this several people said that they were asked the questions they needed to be asked at point of diagnosis by the consultant and they were supported. This was recognised to be very dependent on the consultant or other health care professional you saw. This difference that people experienced supported the need for a check list for health care staff to ensure points of importance to people living with MS were touched on - to standardise the experience. This positive experience included one person saying:

> 'I was asked what I wanted to achieve and was given information to address this.'

It is also important to note that there were a range of people involved in the discussion from the perspective of when they were diagnosed. Of the people living with MS a number of people had been diagnosed more recently (in the last three years) and the groups also included a long term volunteer and a carer for a person living with MS.

The discussion in the original MS Pathway workshop (November 20) also drew out the fact that the Walton Centre cannot provide the full range of services and access recommended in the optimum MS pathway. One of the groups did begin to discuss that some of the support and information needed could be provided closer to home and in the community. This is referenced below.

Summary of the Discussion that took place on Information and Support Needs from Point of Diagnosis

At Point of Diagnosis - Comments on Information and Support Needs

There were a range of comments based on people's experiences at point of diagnosis. These included:

- Some people felt 'confused and bewildered' and also 'unsupported.' This was not dependent on when they had been diagnosed
- 'the group were mainly people who had lived with MS for some time, and it was striking how similar their experiences were in this regard with the more recently diagnosed that had reported in and were present in the groups.'
- One newly diagnosed person commented that they were finding 'this discussion really useful.'
- Some experiences had been different in the past, with contact after diagnosis less structured than it is now. However, even the most recently diagnosed found the six week wait for an appointment after diagnosis really difficult to manage
- Several people said that they felt they needed emotional support at point of diagnosis to work through what they were feeling. One person stated:

  'I was diagnosed at 22 stunned and didn't know what to do…..this really messed with my head for a long time.'
- Several people in both groups acknowledged that they didn't want all the information all at once as they wouldn't be able to take it all in; and too much information could be alarming. In response to this one person suggested that the question that needs to be asked is:
  'How much more do you want to know?'

- The above question linked with the fact that it was important not to assume too much knowledge and this was from someone who had worked in health care for a long time.

- The Getting a Grip course was valued but the length of wait to access the course (Walton Centre) could be anything from 1 to 3 years (pre Covid).
  https://www.mssociety.org.uk/care-and-support/local-support/local-groups/brentwood-chelmsford-group/getting-grips-ms-course

- Digital appointments were discussed and it was agreed they were useful once you had been diagnosed. For the appointments around diagnosis people stated that they need to be face to face wherever possible. This was to ensure body language and how a person was reacting to the information could be picked up more easily.

One important point that people raised is that they blamed themselves for getting MS when they were first diagnosed and thought for some time it was something they did or it was linked to a stressful job. One person said they asked the question:

> 'What have I done to cause this?'

- Positively people said that one of the biggest sources of information and support at this time 'came from organisations outside the clinical team – MS Society/Local groups/Therapy Centres'. People said they would like to be directly referred to these rather than have to initiate finding and attending this support.

- It was discussed in one of the groups that as well as local groups meeting the information needs there was a need to look at how place based community / social prescribing / wellbeing coaches could be used local to where people lived to develop this support.

Emotional Impact of Diagnosis and support / Information Needed

As mentioned in the above section the need for information and support in relation to the emotional response to the diagnosis was frequently mentioned and included:

- Universal desire for either psychological support or peer to peer support (if not at the point of diagnosis very soon after).
- People stated that with some structured emotional support they may feel more able to work with the diagnosis and take control themselves from the point of diagnosis rather than feeling 'abandoned'
- In addition to this people described a need for emotional support in relation to their family, in particular support around telling their children about their diagnosis.
- Much of what people identified they needed was quite 'low level' including peer support. There was discussion about how local counselling and emotional support services along with the local groups could meet some of this need.
- People also discussed the importance of how the information was given at point of diagnosis. Several people commented on how the negative was emphasised - 'You have a chronic degenerative condition.' whilst clinically accurate, this did not give people the impression that there was much they could do to help themselves.

Also for people receiving a progressive diagnosis they remembered being told 'There is nothing you can do.' This was linked to coming off a DMT, but people did not go away with a view that managing their health would or could make a difference.

- The above discussion led to people asking about support and training for health care staff to deliver difficult news in a way that enables people to go away feeling there is still a lot they can do. As one person stated:

> ‘It is important that you don’t go away with the feeling that there is nothing you can do.’ People commented on the fact that this conversation can have an influence on how the disease progresses ‘may even be disease limiting.’

- Activity and Exercise - What do you need to know?
- All present said they didn’t feel the importance of keeping moving and exercising was discussed enough
- Where to go for activity / exercise wasn’t discussed enough, and people weren’t supported in ‘taking ownership of their movement and activity.’
- Many didn’t feel that going to the local gym was an option. This led to some discussion about the partnership between Brio Leisure and the Neuro Therapy Centre in West Cheshire, which was seen as positive but not available everywhere.
- It was mentioned that people think this is only important when you start to have problems with movement. It was recognised that it can be difficult to engage people in exercise and activity but the information is clear.
- One person explained they ‘exercised even more than their routine had been prior to diagnosis.’ They felt they wanted to get as fit as they possibly could to, as they said, ‘deteriorate from the highest point’. This is not for everyone but they didn’t receive any information on the benefits of exercise and activity that they can remember, and got the information they needed online.
- The benefits of exercise and activity are supported by research now e.g. https://mstrust.org.uk/research/research-updates/210203-exercise-good-brain
- People commented that you need to pick the right exercise for you and there needs to be a range of options.
- The difficulty of accessing a neuro physio that you can check in with when needed to support maintaining movement and activity was discussed.
- Digital offer worked really well to keep some people active and remains important for several people now.
- As part of this discussion FES for foot drop and also FES cycling was discussed in the groups. There was a lot of interest in this and frustration expressed at how hard it was to access with some people going private to access it.

Employment / Income / Finances

A range of points were discussed in relation to employment that people felt the need to discuss with someone after diagnosis. All struggled to find a place to have this conversation. People identified that they wanted to think about:

- How do I tell my employer?
- Should I tell my employer?
- What will be the impact of my diagnosis on work?
- One person commented that :

  'Mentally this was one of the hardest things to get through.' and there was a need for counselling/ support to work this through.

- Employment is important and linked sometimes to keeping moving and active – two people stated they got much worse when they finished work and some of that at least was because they were moving less. This was quite recent for one person and they stated the pain got much worse at this point and then they started introducing exercise and activity and the pain lessened significantly.
- Information on benefits and DLA, PIP and life insurance is needed in a timely way linked to discussions about employment. There was some debate as to what timely means – 'too early, too depressing' as it indicates a major change in life in having to give up work etc.

Moving to Secondary Progressive / Being Diagnosed with Primary Progressive MS

Although the focus of the discussion as detailed above was on information and support needs at point of diagnosis several people who took part pointed out the significant information and support needs of people diagnosed with progressive MS or move to progressive MS. They stated they struggled with negative thoughts and a lack of information on how they could respond to and self-manage their condition.

A lot of the information needs are similar to the above discussion relating to exercise and activity, employment and emotional support

Information and Support Needs in relation to DMT's

As there was not sufficient time to discuss this in the session it was agreed that as many from the discussion as could would meet again in early 2022 and add to this discussion. The main points made in the session included:

- A need to be given information on the treatment options with a discussion on why some may not be available / appropriate for them at a particular point in the progression of MS
- A need for clear information on the eligibility criteria for DMT's for progressive MS and a discussion about why they are not eligible for them
- A need to understand the side effects as weighed against the effectiveness of the treatments, several people commented on the side effects
- A couple of people had long term medication and chose to come off, and so far (three plus years) have not experienced any adverse effects to ceasing medication - one member of the group thought their health had improved as a result.
- The importance of understanding the implications of how the DMT was taken with the least invasive being preferred (tablets). One person stated:

  'Injections could leave mark on skin and irritate the skin, some days it would hurt and some days it wouldn't'. For the family also the injection could be hard to watch and no Sharps bins with the tablet was seen as positive
- Several people talked about the difficulty where there is a difference of opinion about whether a person has had a relapse with the people feeling they needed to be listened to more as they had experienced a significant change in how their body worked.

Next steps specifically in relation to production of check list

The following next steps were discussed:

- Dec 21 - write up the discussions
- January 22 - Incorporate the discussions in the report drawing out themes/ questions and suggested points to include in the check list.
- Jan/ Feb 22 - Share report with attendees and identify a smaller working group of about four people from the people who attended.
- Feb 22 - Take report and recommendations to the working group for the MS Pathway action plan - Ian Pomeroy (Consultant Neurologist), Jen Duffy (Divisional Manager Neurology Services, Walton Centre), Sue Thomas (Wilmington Healthcare) and Ruth Austen Vincent (MS Society). Discuss potential timescales for taking forward work on the recommendations.
- Feb / March 22 Meet with / share with health care staff so that existing good practice can be identified and support the development of a usable check list ensuring that this builds on existing good practice.
- March - May 22 Develop dialogue on a checklist that addresses the discussions that take place above. This will bring together the discussion of health care staff and people living with MS and will include sharing points and ideas via email etc. and some digital on line conversations where it is possible to set this up given time constraints particularly for health care staff.
- By Autumn 22 Take to relevant committees in Walton and Neuro Science Program Board.
- Winter 22 onwards - Enable the use of this with health care staff via communications and team meetings etc.
- After 12 months review effectiveness of the check list with health care staff and people living with and affected by MS, and develop the check list as required by the review.

Acknowledgements

A thanks you to members of the MS Society Stakeholder Engagement team who supported this event to take place.

A huge thanks to the people living with MS who gave their time and were prepared to share difficult memories and experiences in relation to their journey with MS.

A thanks to the health care staff who have supported the delivery of services and information to date and who will work with the information here to develop this further.

Appendix 1

Focus Group – Information you would like / like to have had when diagnosed particularly on treatment options – 30/11/21

10.30–12.45

AIM – To talk through with people living with MS about their experience of information on diagnosis and about Disease Modifying Treatments.

This information will be used to create a checklist that in particular consultants, nurses and other health care staff can use when talking to people living with MS.

10.30–10.50	Introduction – Where this has come from and why the questions were raised at the workshop in November 20 (5 minutes of this will be people moving over to break out rooms on zoom)
10.50–12.20	Workshop / Discussion What information can you remember being given when you were diagnosed? (10.50 – 11.00) Of the information you were given what has proved to be most useful? (11.00 – 10.10) What else would you have liked to receive information about? - Need to point this discussion towards that point in the survey you have Rob about the fact that 70% of the people interviewed didn’t know about neuro physio. (11.10 – 11.30)
Break	**11.30–11.50** When would have been the right time to receive that information? How would you like to receive it? (Verbally face to face or digital or in writing or on web links etc.) (11.50–12.15) Two points to feedback (12.15–12.25) Additional thoughts and questions that may support the above discussion specifically around DMT’s What can you remember being told about DMT’s? What helped you make a decision about which DMT to take? What else would have supported you in making that decision? How would you like to receive the information about DMT’s? Did you receive the information you needed when you changed to a different DMT or came off the DMT’S?
12.25–12.40	Sum up and next Steps – Specifically small working group to put together check list

Appendix 2

Break Out Group Write Ups:

Group 1

Discussion at point of diagnosis:

- Several times it was stated that there is too much negative information given to start off with – One person remembers

  'You need to remember you have a chronic brain disease and there won't be a cure in your life time'

- One person explained that they had to go privately as couldn't get a referral to Walton and when they were diagnosed they weren't offered anything - shown their MRI scan, diagnosed in 2019, still haven't seen an MS nurse. (Info on the Nurse advice line was passed on to them)
- Another person was diagnosed at Preston and when they asked to be referred to Walton this was a revelation to them. They said even though elements of the service could improve they were extremely impressed with what they were offered.
- A newly diagnosed person had been told DMT's weren't suitable and were accessing support from the local authority OT's
- This led to a discussion between people that you can change your consultant if you are not happy.
- Digital appointments were discussed and it was agreed they were great once you had been diagnosed. For the appointments around diagnosis it needs to be face to face as can pick up on body language and how a person is reacting to the information more easily.
- Put on Mitoxantrone and then Capaxone with an injection every day - Preferred the tablet as less invasive and takes up less time and easier to explain to children.
- Several people commented on the importance of emotional support at this point as for several years they 'stuck my head in the sand'. They felt they could have done more early on in terms of self-management

(diet and exercise) if early on they had recieved some emotional support.

- This information needs to be presented positively. Info on what MS is and what the individual can do

FES: lots of interest from people who hadn't heard about it when it was described by the people who use it:

- Can support walking
- Very hard to get hold of
- One person had it paid for by local MS group
- Doesn't work for everyone
- Need to stick with it and needs adjusting
- Meeting with consultants at first and then when move to secondary progressive again a negative way of presenting information - there is nothing that can be done now.

What do you need to be asked when you are diagnosed? / Questions that could support finding out your background.

> 'You need to be steered by the clinicians but they can't do that if they don't know anything about you.'

> 'Completely agree … clinicians need to be alert to patient level of understanding and the needs and responsibilities they have in their life'

- How much more do you want to know? One person said and others agreed that they didn't want to hear everything at point of diagnosis and didn't join a local group then as didn't want to see people using wheelchairs etc. then
- What's your job?
- What's your home / family situation?
- What do you want to achieve? One person said they were asked this by the first consultant they had at the Walton centre

- When giving information important not to assume too much information even if the person has worked in health care
- Person who was a one parent family when they got the diagnosis – They wanted to talk about how they needed to be active for as long as possible.
- People said these questions would support them further in being

‘Partners in our own health care.’

- Sometimes you don’t know what to ask for – this led to a discussion about how some were offered physio and OT when they needed it and some weren’t.
- It is important to know and be clear that the person shouldn’t blame themselves for getting MS as several commented that they thought for some time it was something they did or it was linked to a stressful job. One person said they asked the question:

‘What have I done to cause this?’

- Need to be given information on trials - several people were happy to take part when they were diagnosed

Information / Guidance needed in activity and Exercise

- All present said they didn’t feel the importance of keeping moving and exercising was discussed enough
- Where to go for activity / exercise wasn’t discussed enough, weren’t supported in ‘taking ownership of their movement and activity.’
- Didn’t feel that going to the local gym was an option. Led to some discussion about the partnership between Brio Leisure and the Neuro Therapy Centre in West Cheshire.
- People think this is only important when you start to have problems with movement.
- One person explained they ‘exercised even more than their routine had been.’ They felt they wanted to deteriorate from the highest point they could be at so they did a number of triathlons.

- Benefit of being active is supported by research now – send links out
- People commented that you need to pick the right exercise for you and there needs to be a range of options
- The difficulty of accessing a neuro physio that you can check in with when needed to support maintaining movement and activity was discussed.
- Digital offer worked really well to keep some people active and remains important for several people now.
- Need information about Motability
- Info and support for cares/ family members.

Seeking out Information on google to plug the gap

- ‘Knowledge is power but you need to know how to use it.’
- Can be unhelpful to google information ‘don’t want to feel bombarded with it’. Several people agreed ‘This can make you feel scared.’
- Need to go home think about it and write questions down
- The volunteer group at Walton clinics was mentioned as a good source of information

Support / Info about Employment

- How do I tell my employer?
- Should I tell my employer?
- ‘Mentally this was one of the hardest things to get through.’ - related to acceptance of the condition
- Need counselling support
- Need to be able to talk through the impact of the diagnosis on work.
- Talked about the fact that employment may be more of an option now post covid.
- Employment is important and linked sometimes to keeping moving and active – two people stated they got much worse when they finished

work and some of that at least was because they were moving less. This was quite recent for one person and they stated the pain got much worse at this point and then they started introducing exercise and activity and the pain lessened significantly

(Brain Charity employment support info was circulated)

Health Care Staff need training in breaking bad news – Importantly this point was raised by someone who had worked extensively in health and agreed with by the group

- ‘It is important that you don’t go away with the feeling that there is nothing you can do.’
- People commented on the fact that this conversation can have an influence on how the disease progresses ‘may even be disease limiting.’

Importance of Emotional Support

- Several comments about the importance of having access to emotional support from point of diagnosis. ‘Diagnosed at 22 stunned and didn’t know what to do…..this really messed with my head for a long time.’
- Need more regular access in community – wellbeing advisers / social prescribers to support this?
- Need support to ensure access to activity and exercise and to work through employment
- Help with telling family / children
- This also linked to the importance of support around addressing fatigue

Brief Discussion on DMT’s and Info Needed

(Agreed this needed longer so will revisit in 2023)

- First consultant explained the different DMT’s and asked

  What do you think?
- One person said there was a choice of two tablets and several commented on the bad side effects

- The ease of taking a DMT was important for people with tablets being preferred by most to injections
- In terms of injections ‘could leave mark on skin and irritate the skin, some days it would hurt and some days it wouldn’t’.
- For family also the injection could be hard to watch and no Sharps bins with tablet was seen as positive
- Real frustration from people diagnosed with progressive MS no or very little access now to DMT’s. Lack of information on who the DMT’s for progressive MS could be available to.
- Wondered whether the consultant might think they are not bad enough for a trial / need to understand if they don’t fit the criteria.
- Talked about the difficulty when there is a difference of opinion with health care staff on whether they have had a relapse or not, and the impact this has had on peoples access to DMT’s

Group 2

Information needs and timing of information:

- Recently diagnosed people in 20’s and 30’s , reporting into the group members (not attendees) had a diagnosis but no further information from the neurologist or nurse until the follow up after 6 to 8 weeks. Majority view was they left feeling confused and unsupported with no access to any other help
- Overwhelming agreement that **more information is needed at the point of diagnosis** – the group were mainly long term survivors of MS, and it was striking how similar their experiences were in this regard with the more recently diagnosed that had reported in.
- Universal agreement that they all **felt confused, bewildered and unsupported** at the point of diagnosis, and the long gap before in a follow up appointment exacerbated these feelings of not being in control of their health
- **Universal desire for either psychological support or peer to peer support if not at the point of diagnosis very soon after**.

- Common feelings in the group that they had been “forgotten” once the diagnosis had been made and were pretty much left to their own devices at this point
- **Particularly appreciative of the way the MSS, both through its helpline and local groups** were able to support, inform and educate, but some frustration that they had to seek out that contact information themselves rather than been given the information at point of diagnosis.

What’s needed?

- Contacts **–** Skills – Information
- **Early access to psychological support services**
- Diet and exercise (those diagnosed for longer never received any advice re: exercise for example)
- ‘Getting a grip’ was valued but the length of wait to access the course (Walton Centre) could be anything from 1 to 3 years (pre-Covid)
- **A wide range of advice, ideally from a multi-disciplinary team.**
- After the visit with the Neurologist for diagnosis, some immediate time with the nurse to get further advice and answer questions
- Ability to take someone in with you at the point of diagnosis
- **The biggest support ,** (universal from the group), **came from organisations outside the clinical team** – MSS/Local groups/Therapy Centres, again would want to be **directly referred to these** rather than have to initiate finding and attending etc. by themselves
- **FES – a big discussion**, the group wanted more information on this and access to the machines much, – i.e. what an individual could do much earlier and didn’t want to have to fight for it.
- Information packs on MS, treatment and care that could be source through local GP surgeries
- Information on benefits and DLA and PIP in a timely way (would probably need further teasing out in another session, some debate as to what timely means – ‘too early, too depressing’ as it indicates a major change in life in having to give up work etc.)

- **Standard information would be welcomed, there was too much variation in current systems** (as an aside most in the group were diagnosed between 6 and 25 years ago)
- **Information on Psychological support and space for carers and family members as well as selves**
- Importance of the right information at the right time – too much about the potential for the disease progression can be alarming not reassuring

DMT Discussion (Most attendees not taking a DMT (Progressive) Limited experience in the group).

- Most of the group expressed a need for more information on DMTs, how they work and what the side effects are, and would like that information at the point of diagnosis
- Would welcome further discussions with neurologists on the potential use/value of all treatments including DMT's
- Some frustration expressed at the **lack of DMTs for progressive, and frustration that they were not told why they weren't offered DMT's**
- Some basic information on Disease Modifying Therapies (DMT's) would be welcomed, including the reasons why they can't be prescribed
- A couple of members have had long term medication and have chosen to stop, and so far (three plus years) have not experienced any adverse effects to ceasing medication, one member of the group thought their health had improved as a result.
- In one case a request for DMT's have been rejected and the patient has been told that they would only receive medication is their MS worsens – (this is historical, not in the last three years)

In some cases the only route to a DMT is through private clinics

Appendix 3

Attendees:

- North Wales 5 attendees
- Merseyside 4 attendees
- West Cheshire 3 attendees

MS Society

- Ruth Austen-Vincent – Stakeholder Engagement Officer
- Armanda Winwood – Stakeholder Engagement Officer
- Yvonne Trace – Stakeholder Engagement Officer
- Ann McDougal

We’re the MS Society.

Our community is here for you through the highs, lows and everything in between. We understand what life’s like with MS.

Together, we are strong enough to stop MS.

Contact us

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▶ Let’s stop MS together