

# The BartsMS Navigator of Multiple Sclerosis Care

Supporting you to manage life with MS



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## Do you (think you) have MS?



**“I think I may have MS”**

Please see your GP and ask for a referral to neurology.

If you have symptoms, such as loss of balance, problems with your vision in one eye, or a weak limb, and these have come on suddenly, within the past week or so, please call 111, visit your local A&E, or email us at [bartshealth.attackms@nhs.net](mailto:bartshealth.attackms@nhs.net)



**“I have been diagnosed with MS”**

**Please read on!**

## Introduction

**The BartsMS Navigator** is a resource for people living with [multiple sclerosis](#)<sup>1</sup> (MS). It is written by the BartsMS team, which is based at Barts Health NHS Trust and Queen Mary University of London (QMUL). Whilst this is written with people with MS (pwMS) using our service at Barts Health in mind, much of it will be of interest for pwMS irrespective of where they live. You should be able to read each chapter as a standalone, so you do not need to read it all at once/front to back.

Please tell us what you think about the Navigator; we are keen to receive your feedback. For comments and suggestions please use the following email:

[bartshealth.bartsmsnavigator@nhs.net](mailto:bartshealth.bartsmsnavigator@nhs.net)

## Why “BartsMS”?

For most pwMS, BartsMS simply means “Your MS service at Barts Health.” The reason we do not simply call ourselves Your MS service at Barts Health is that BartsMS covers the wider team. It includes both clinicians (doctors, nurses, other health care professionals, such as our neuro-physiotherapist, MS clinic coordinator and the clinical trials team) and people with no clinical background or training, such as colleagues who solely do basic, laboratory-based research. Jointly, clinicians and basic researchers work as a team helping each other to understand MS better and coming up with new treatments, guidelines, and services.

### **For Example:**

[David Baker, a Professor of Neuroimmunology at QMUL, has been a member of BartsMS for more than 15 years. Although he is not clinically trained, his fundamental insights and understanding of the nervous and immune systems, builds the knowledge of the whole team helping pwMS manage MS.](#)

A further group of people under the umbrella of BartsMS are pwMS contributing to the team through their lived experience of MS. This may be through a one-off activity such as helping to review one of the documents we produce (for example, a guideline or a plain English summary of a research project), or a more permanent

role, such as membership of a trial steering committee. Some BartsMS volunteers run their own initiatives, blogs, websites and YouTube channels raising awareness about MS in general and issues around their lives with MS.

### **For Example:**

Christine Chapman, a digital editor living with MS, has been part of BartsMS for nearly 10 years. Combining her professional background with her experience of MS, Christine has been instrumental in the design and management of ChariotMS, a first-ever trial of disease modifying treatment in people with advanced MS. She also set up the website for the trial. For further information: [www.chariotms.com](http://www.chariotms.com)

To learn more about the team, please scroll down to chapter 2.

### **Meet the team**

Here you will find a list of the members of the BartsMS team. Some names are naturally subject to change; trainees and fellows are on rotation, and often stay only for 6-12 months, whilst others are part of our permanent staff.

#### **Patient pathway coordinators (PPCs, formerly known as secretaries)**

Neurology telephone numbers are 020 3594 1195 and 0203 594 1196 and generic email: [bhnt.neuroscienceppc@nhs.net](mailto:bhnt.neuroscienceppc@nhs.net)

You can also email the PPC associated with your consultant:

- Ms Karen Wong [Karen.wong@nhs.net](mailto:Karen.wong@nhs.net) (working with Professor Ruth Dobson, Dr Sharmilee Gnanapavan, Dr Monica Marta, Professor Schmierer and Dr Turner).

Please use these contacts for any issues with clinic appointments, or if you need a copy of your clinic letter.

#### **Administrators (Neurology Day Case Unit/Ward 11D)**

Telephone 020 3594 0637; [bartshealth.ward-11D@nhs.net](mailto:bartshealth.ward-11D@nhs.net)

- Ms Sultana Begum
- Ms Salini Bhaskar

Please contact Sultana or Salini for any issues relating to appointments on our Day Case Unit (Ward 11D), for example your lumbar puncture.

## **MS Clinic Coordinator**

The MS Clinical Coordinator is responsible for arranging our weekly neuroinflammation multi-disciplinary team (MDT) meetings and supports the remote monitoring programme. Please contact Ms Husna Ahmed the coordinator by email ([bartshealth.mscoordinator@nhs.net](mailto:bartshealth.mscoordinator@nhs.net)) should you need any support tools, for example a cardboard [nine-hole peg test](#).

## **Consultants** (please contact the respective PPC to get in touch)

- Professor Ruth Dobson, Consultant Neurologist
- Dr Sharmilee Gvanapavan, Consultant Neurologist, Clinical Lead Neurology
- Dr Monica Marta, Consultant Neurologist
- Prof Klaus Schmierer, Medical Lead BartsMS, Neurology Research and Day Case Unit (Ward 11D)
- Dr Ben Turner, Consultant Neurologist

## **Neurology Registrars and Fellows:**

- Dr Mohammad Aboulwafa (Clinical Research Fellow)
- Dr Lisa Clayton (Neurology Registrar)
- Dr Rania Mustafa (Neurology Registrar)
- Dr Yao Zhang (Clinical Research Fellow)

## **MS Clinical Nurse Specialists**

- Ms Grace Anjorin (MS Clinical Nurse Specialist) [grace.anjorin@nhs.net](mailto:grace.anjorin@nhs.net)
- Ms Freya Edwards (MS Clinical Nurse Specialist) [freya.edwards@nhs.net](mailto:freya.edwards@nhs.net)
- BartsMS Clinical Nurse Specialist team generic email:  
[bartshealth.bartsmsnurses@nhs.net](mailto:bartshealth.bartsmsnurses@nhs.net)

## **Nurses (Ward 11D):**

- Ms Adedamola Adetosoye (Healthcare assistant)
- Ms Ruksana Begum (Staff Nurse)
- Ms Ana Jaramillo (Junior Sister)

- Ms Sumeeya Mona (Staff Nurse)
- Ms Emma Ridgway (Junior Sister)
- Ms Tatiana Sayali, Nurse Lead and Manager, Neurology Research and Day Case
- Ms Theresa Velarde (Matron)

### **Neuropharmacists:**

- Ms Joela Mathews
- Mr Charles Tugwell

### **Clinical Research Team**

- Dr Bader AliMohammed (Clinical Research Fellow)
- Ms Kimberley Allen-Philbey (Senior Clinical Trials Manager)
- Ms Katila George (Research Nurse)
- Prof Gavin Giovannoni, Professor of Neurology
- Dr Anastasiia Meryndia (Clinical Research Fellow)
- Ms Norbethangelie Villegas (Research Nurse)
- Dr Andrea Stennett (Research Neuro-Physiotherapist)

### **Non-clinical academics**

- Dr Francesca Ammoscato, Senior Lab Scientist
- Prof David Baker, Professor of Neuroimmunology
- Dr David Holden, Lab Scientist
- Prof Angray Kang, Professor of Immunotechnology

### **Personal assistants (academic)**

- Ms Emilia Powell (Prof Gavin Giovannoni) [giovannoni.pa@gmail.com](mailto:giovannoni.pa@gmail.com)
- Ms Yvonne Robinson (Prof Klaus Schmierer) [y.robinson@qmul.ac.uk](mailto:y.robinson@qmul.ac.uk)

### **Design and PPI advisor**

- Dr Alison Thomson, Lecturer in Patient Public Involvement and Public Engagement in Science

## Patient and Public Involvement and Engagement (PPIE) experts

- Mr Patrick Burke (<https://www.aid4disabled.com/>)
- Ms Christine Chapman (<https://www.linkedin.com/in/christine-chapman-b882b27/>)
- Ms Rachel Horne (<http://rachelhorne.co.uk>)
- Mr John Miers (<https://johnmiers.com/>)
- Mr Dominic Shadbolt (<https://dominicshadbolt.com/>)

Further PPI contacts can be provided on request. Please get in touch if you would like to support BartsMS in a PPIE role!

## The team at their Away Day in Regents Park 2022





## Medical treatments for people with multiple sclerosis

In order to optimise the time, you spend in your consultation with your Neurologist, MS specialist nurse, or other health care professionals at BartsMS, we have summarised a few key points about the medical treatment of people with multiple sclerosis (pwMS). Further information will be provided as applicable to your individual situation.

The medical treatment of pwMS can be divided into (i) drugs targeting specific symptoms, for example limb stiffness (“spasticity”), bladder dysfunction, depression, and (ii) drugs that actually alter the disease itself - disease modifying immunotherapies (DMTs).

This section deals with DMTs.

DMTs are used to alter the abnormal body behaviour that results in damage to nerves causing the symptoms in MS. These abnormal processes include inflammation, demyelination (loss of the insulating sheath of nerves) and nerve loss in the [central nervous system](#).

In the UK, there are currently 18 licensed DMTs available for the treatment of pwMS. Each of these can be prescribed at Barts Health.

In addition to the licensed DMTs, the BartsMS team may be able to offer you:

- (i) participation in a clinical trial, and/or
- (ii) treatment using immunotherapies that are currently not licensed for pwMS but for other indications (for example drugs used to treat cancer may be used to treat pwMS).

Except for some DMTs that are still undergoing clinical trials (and you would always be made aware should this apply to you), immunotherapies used at Barts Health have all been shown to be effective in altering the disease course of pwMS.

Provided certain eligibility criteria, dictated by NHS England, are fulfilled, all DMTs offered at Barts Health are funded by the NHS.

In preparation of, and/or as a follow-up to, your consultation in clinic or on the ward

we encourage you to visit evidence-based resources for pwMS, including the following:

- [The MS Trust](#)<sup>2</sup>(MS Decisions aid)
- [The MS Society UK](#)<sup>3</sup>(DMT Decision tool)
- [The ShiftMS information pages](#)<sup>4</sup>
- [The CRIMSON Project Decision Aid](#)<sup>5</sup>
- [The ClinicSpeak DMT comparison tool](#)<sup>6</sup>

It is not mandatory to read all of the above word by word. However, they provide an overview of which DMTs are currently available. What is best for you will depend on individual factors, so the discussion with your consultant and MS clinical nurse specialist will be key for your individual decision.

The BartsMS team will be happy to provide further information and answer any questions. However, please bear in mind the time allotted for appointments is limited in line with NHS guidance and Trust policies. As a result, we may not always be able to address each question during a single appointment. Should this be the case we will endeavour to arrange further follow-up, as required (telephone, email, additional appointments).

[Please ask the team about ongoing clinical trials and/or treatment with off-label immunotherapies, such as haematopoietic stem cell transplantation \( HSCT\).](#)

To keep up to date with the latest news in MS research, please feel free to visit our [Blog](#)<sup>7</sup> and/or Prof Giovannoni's [MS Selfie](#)<sup>8</sup>.

An update of the above, and information about symptomatic medical treatments will be included in our next edition of the MS Navigator.

## **[About our Neuroscience Day Case Unit \(Ward 11D\)](#)**

**\*\*Please note that Ward 11D is only open 9am - 5pm, Monday to Friday, and does not accommodate people overnight. \*\***

The Day Case Unit is what it says on the 'tin': Admissions for the day, either for diagnostic procedures (lumbar punctures, etc), treatment with some disease modifying therapies (DMTs) and clinical trials. Once you and your team (neurologist,

MS clinical nurse specialist, others) have agreed on a treatment, you may be referred to Ward 11D. Should this be the case, a member of staff from the ward will contact you to book your appointment (this may take a couple of weeks).

Here is some general information to help prepare you for your appointment with the team on 11D. More specific information related to your treatment or other intervention will be sent to you either via email or post.

### **Travel arrangements:**

- **Public Transport:** you can travel to the Royal London Hospital by Train, Tube, Bus, Car/Taxi or Bike. Please note, if you travel by car, parking is quite limited around the hospital. We therefore advise you to use public transport whenever possible. The closest tube station is Whitechapel which is opposite to the hospital and approximately a 6 minutes' walk (with step-free access) from the station. The Whitechapel station is served by the Elizabeth Line, Hammersmith & City Line, District Line and the London Overground. Please visit the website <https://www.bartshealth.nhs.uk/the-royal-london> or click [Transportation](#) for more information about travelling to the hospital.
- **Patient transport:** If you are unable to travel to your appointment by public or private transport, you might be eligible for patient transport. To check your eligibility, and/or to book transport, contact the Patient Transport Service on 02077673344; The department is open Monday-Friday between 9-5pm.

**\*\*In order to use the patient transport service, you would need to book 72 hours in advance of your appointment date\*\*.**

## Contact

Ward 11D is located on the 11th floor of the Royal London Hospital. When you arrive at the hospital, you can either use the main entrance (off Whitechapel Road), or the Stepney Way entrance. Once in the building, please follow the signs to **Lift Core 5** and type in “11” on one of the displays to identify the lift (5A, 5B, 5C, or 5D) that will take you to the 11th floor.

The telephone number for Ward 11D is 020 359 40637/8. The email address is [bartshealth.ward-11d@nhs.net](mailto:bartshealth.ward-11d@nhs.net).

## What to expect on the day of your appointment on 11D

- Depending on the reason you have been invited to 11D, we will often take your observations for example, heart rate, temperature and blood pressure.
- Some infection control precautions are in place to keep you safe. For instance, we try to maintain some distance between patients.
- Accompanying persons are generally not allowed to stay in the treatment rooms with you, again in the interest of infection safety. They may wish to visit the cafeteria on the 5th floor or sit in the waiting area outside the unit until your procedure has been completed.
  
- Should you come for an infusion treatment, a cannula will be inserted, and some pre-medication (tablets) may be given prior to your infusion. If a cannula is being inserted, we will remove it once the treatment is completed and before leaving the unit.
- The time required varies depending on the type of procedure (diagnostic or treatment). You will get specific information about this from the nursing team.
- It is advisable to have a post infusion/ investigation travel plan just in case you require some assistance to get home if you feel unwell. For example, if you travel to the hospital using the tube, depending on how you feel after your infusion, you might need to return home via taxi or have someone pick you up from the hospital.

## Other useful information about ward 11D

- The team on 11D are unable to provide **sick notes**; if needed these can be provided by your GP.
- You may take **electronic devices** to your appointment, for work or entertainment, for example your iPad, mobile phone, laptop computer. Please bring earphones. You can charge your device on 11D. Alternatively, you could bring a book or paper to read. You may access the hospital NHS WiFi ([Network:NHS Wi-Fi](#)) free of charge. Please bear in mind, signal strength might vary such that streaming may not be possible at times.
- If you have a favourite programme, you really want to watch or listen to, bring it as a podcast downloaded to your appointment time.
- Due to **air-conditioning**, the unit may at times get a bit chilly, so we recommend you bring a jumper or cardigan.
  
- If you have any **dietary requirements**, you are welcome to bring your own food and drink. We provide sandwiches, yoghurt, fruit, juice and crisps (free of charge). We can provide hot drinks but please bring your own mug/keep cup.
- The **canteen** on the 5th floor serves hot food and drinks. Please note, you will not be able to visit the canteen during your procedure or treatment, but you usually can before or after your visit on 11D. If a friend or family members accompanies you , they are able to purchase food and/or drink for you to consume on the ward. There are several food outlets and cafes in the area.

## Research

### **BartsMS Research ([bartshealth.mstrial@nhs.net](mailto:bartshealth.mstrial@nhs.net))**

This includes clinical trials as well as basic science (laboratory) studies involving people with MS (pwMS). Our overarching goal is to improve outcomes and quality of life for pwMS. This would obviously not be possible without the help and contribution of pwMS themselves, through participation in a drug trial, joining a non-interventional study, such as the MS Register, or donating blood or other body fluids (for example, cerebro-spinal fluid, urine). Through research, innovation can take place. For example, enabling new treatments to be tested so that they become available as part of routine NHS care.

### **Who can take part in research?**

In short - anyone!

It does not matter if you are brand new to research and have never taken part in a clinical trial before. We conduct a range of different clinical trials. For example, some trials for people who are newly diagnosed with MS and other trials for people who have been diagnosed with MS for longer. Each clinical trial can only enrol participants who match the defined characteristics called eligibility criteria, so please bear in mind that “being offered” participation may not always lead to actual enrolment in a trial because you do not fulfil certain criteria. Something simple, such as an abnormal laboratory test result may mean you cannot take part in a specific study. However, there are usually several studies on offer, so that more likely than not you will be able to join one of our studies.

## **How does a clinical trial differ from standard clinical care?**

There are studies where a one-off donation of a few drops of drop blood is all that is required. Clinical trials of new interventions (drugs, exercises, etc.) usually require repeated and more frequent visits to the hospital than you would routinely have. Some patients enjoy seeing the BartsMS team more often, but there are times when you feel your commitment is being tested. Rest assured; we will always try making this as enjoyable as possible for you.

The design of each clinical trial is different which means they require different commitments from you. The time taken at each visit will depend on the number and type of tests/ assessments involved. Most trials will reimburse you for your travel costs, so please keep your receipts or show proof of purchase and we can sort it out for you.

As well as clinical trials that involve medications, devices or behavioural interventions, you may consider taking part in observational studies. Such studies collect data via questionnaires or a review of your medical notes.

## Trials Overview

Clinical Trial	Trial Type	Principal Investigator(s)	Trial Aims and Objectives	Recruitment status *	Start-End Date	Further information sources
<b>ADAMS</b>	Observational	Dr Ruth Dobson and Dr Ben Jacobs	To find out whether the genes that contribute to MS risk are the same or different for people of non-European ancestry, with a focus on people from African and South Asian backgrounds.	Open to recruitment	Aug 2021-Aug 2031	<a href="https://app.mantal.co.uk/adams">https://app.mantal.co.uk/adams</a>
<b>AttackMS</b>	Interventional	Professor Klaus Schmierer	AttackMS will investigate whether very early treatment with the drug natalizumab (Tysabri®), licensed for rapidly evolving severe MS) facilitates lesion repair through a process called	Open to recruitment	Oct 2024-Oct 2025	<a href="https://www.clinicaltrials.gov/ct2/show/NCT05418010">https://www.clinicaltrials.gov/ct2/show/NCT05418010</a>  Email: <a href="mailto:bartshealth.attackms@nhs.net">bartshealth.attackms@nhs.net</a>



Clinical Trial	Trial Type	Principal Investigator(s)	Trial Aims and Objectives	Recruitment status *	Start-End Date	Further information sources
			“remyelination” when given within 14 days after a first manifestation of inflammatory demyelination.			
<b>ChariotMS</b>	Interventional	Professor Klaus Schmierer	Testing the effect of MAVENCLAD® (cladribine tablets) on MS. The primary outcome is upper limb function measured using the Nine-hole-peg-test.	Open to recruitment	Jul 2021-Dec 2024	<a href="https://www.chariotms.com">https://www.chariotms.com</a> <a href="https://clinicaltrials.gov/ct2/show/NCT04695080">https://clinicaltrials.gov/ct2/show/NCT04695080</a> Email: <a href="mailto:bartshealth.chariotms@nhs.net">bartshealth.chariotms@nhs.net</a>
<b>EBV-modified extracellular vesicles in MS</b>	Interventional	Dr Ruth Dobson	To study small fragments of cells, called extracellular vesicles, and look for evidence that they are involved in onset and/or	Open to recruitment	Jan 2023-Jul 2025	Email: <a href="mailto:trackMS@qmul.ac.uk">trackMS@qmul.ac.uk</a>

Clinical Trial	Trial Type	Principal Investigator(s)	Trial Aims and Objectives	Recruitment status *	Start-End Date	Further information sources
			progression of multiple sclerosis.			
<b>FREVIVA</b>	Interventional	Dr Sharmilee Gnanapavan	Time to confirmed disability progression in non-relapsing SPMS.	Open to recruitment	Jul 2024-Dec 2024	<a href="https://clinicaltrials.gov/study/NCT06141486">https://clinicaltrials.gov/study/NCT06141486</a>
<b>FREXALT</b>	Interventional	Dr Sharmilee Gnanapavan	Annualised relapse rate and composite confirmed disability worsening in relapsing MS.	Open to recruitment	Jul 2024-Dec 2025	
<b>MS Register</b>	Observational	n/a	To increase our understanding of	Open to recruitment	2011- Ongoing	<a href="https://ukmsregister.org/">https://ukmsregister.org/</a>

Clinical Trial	Trial Type	Principal Investigator(s)	Trial Aims and Objectives	Recruitment status *	Start-End Date	Further information sources
			living with MS in the UK.			
<b>PAMMS</b> (Pregnancy and methylation changes in MS)	Observational	Professor Ruth Dobson	To understand the molecular mechanisms underlying inflammatory disease remission during pregnancy. The primary objective is to carry out genome-wide methylation analysis in CD4+ and CD8+ T-cells over the course of pregnancy and early postpartum period in women	Open to recruitment	TBC	Email: pamms@qmul.ac.uk

Clinical Trial	Trial Type	Principal Investigator(s)	Trial Aims and Objectives	Recruitment status *	Start-End Date	Further information sources
			with MS.			
<b>SIZOMUS</b>	Interventional	Dr Sharmilee Gnanapavan	To assess the safety and effectiveness of a drug called ixazomib, also called Ninlaro®, in people with MS.	Open to recruitment	Sep2020- Sep2027	<a href="https://clinicaltrials.gov/ct2/show/NCT03783416">https://clinicaltrials.gov/ct2/show/NCT03783416</a>

## **Remember:**

- Trial participation is never mandatory - you do not have to participate, and you can terminate your participation at any point.
- Take your time to decide and discuss it with family members and/ or friends if you wish.
- The trials team are here to answer your questions so that you can make an informed decision.
- Should you decide to take part, we will support you throughout your trial journey.

## **How to join a clinical trial at BartsMS**

If you would like to be considered for a clinical trial we are involved in, please email us at [bartshealth.mstrials@nhs.net](mailto:bartshealth.mstrials@nhs.net). Alternatively, you can ask your neurologist or GP to send a referral letter to the Principal Investigator (lead doctor) of the trial. A member of the trial team will then contact you for more information and to discuss the next steps.

## **Remote Monitoring**

### **What is Remote Monitoring?**

Remote monitoring is one of the support services we provide for people with MS. It offers the opportunity to self-monitor, self-manage and engage with your MS team about how to manage MS symptoms over time. We offer remote monitoring to all patients with MS. Here we share why we monitor and what is expected of you so that we can better support you to manage your MS symptoms.

### **Why monitor People with MS?**

We monitor people with MS for a number of reasons. The key reasons are:

- The symptoms of MS vary from individual to individual and even change from

day to day, so it is important to note how these affect you over time.

- It allows the BartsMS team to monitor changes in disability over time and to see whether or not current treatment is working for you.
- It allows the team to have discussions with you about whether or not additional support (e.g physiotherapy, occupational therapy, continence team, dietician etc) is needed based on the challenges you identify.
- It helps the team to provide the necessary support and care you need at the right time and in the right place.
- It helps us to support you with the tools you need to help to manage the symptoms of MS.
- We can use this information to identify people for, and or raise the awareness of, upcoming research, keeping you informed and up to date with MS research!

## What we expect of you

Prior to your clinical appointment with your neurologist, a member of the BartsMS team will make contact either via telephone or email and ask you to complete **5 key assessments at home**. We call this **remote monitoring**.

These assessments will:

1. provide the BartsMS team with a snapshot view of your walking, cognitive and upper limb ability.
2. add value to your discussions with your neurologist and help us to provide the support you need.

## These assessments include:

- Cardboard nine-hole peg test (c9HPT)- This gives us information about your arm and hand function. We will post one to you if you do not have one at home.



- Timed 25 Foot Walk Test (approximately 7.62 metres – This gives us information about your lower limb function and walking speed.
- The WebEDSS- This measures MS disability (you can complete this assessment at <https://edss.clinicspeak.com/#/> ). *This assessment is also important for people on DMTs to ensure continued eligibility for your treatment.*
- The ABILHAND - this is a questionnaire about how you manage daily life activities using your hands. *(We will send this to you in an email or via post)*
- A brief cognitive test (online) called the Symbol Digit Modalities Test *(we will send the link needed to complete this to your email).*

We have video clips of these assessments on the Clinicspeak website at [www.clinicspeak.com](http://www.clinicspeak.com) so you can have a look and see how they are done in your own time at home. Please note that due to data protection rules we are not able to view your scores from the Clinicspeak website. Therefore in order for us to use them you would need to share your results with the team via the BartsMS email address: [bartshealth.bartsmsdata@nhs.net](mailto:bartshealth.bartsmsdata@nhs.net)

## Recording your results

Once you have completed your assessments, we ask that you record your scores in the table which is embedded in the remote monitoring email. Once completed send your results to email: ***bartshealth.bartsmsdata@nhs.net***

See example below of how to record your results:

Dominant hand	Left, or right?	Right hand
---------------	-----------------	------------

Date	Nine-hole peg test (sec)				Timed 25 Foot walk		Notes (eg use of a cane/walker/orthotic device)	WebED SS score
	D1	D2	ND1	ND2	1st test	2nd Test		
5/Mar/2022	15	20.2	25.0	35.5	10s	10.4	Stick x1	6.5

**D = dominant hand, ND = non-dominant hand. 9HPT = nine-hole peg test. T25FW = Timed 25-foot walk.**

### How will we use this information?

This information will be recorded as part of your clinical records which helps both you and your MS team make the most of your consultation. Once you complete the assessments you can return the scores to the BartsMS email account **bartshealth.bartsmsdata@nhs.net**. All our correspondence about remote monitoring will come from this account.

### How will we contact you?

Ideally, we will contact you in advance of the clinic appointment with your neurologist. We usually make the initial contact via telephone. We will also check to see whether you have any preferences for how you wish to be contacted (e.g post, email, telephone). We want to make this as easy as possible for you.

Please note that, when we contact you, you might see our number as ‘**Unknown caller ID.**’ This is because we are contacting you from the hospital telephone.

Another important thing to note, if you do not have a personalised message on your



voicemail, we will not be able to leave a message to let you know that we tried to contact you.

We are always happy to be contacted by you if you have any further questions or comments about what we are doing. You can contact us at:

**[bartshealth.bartsmsdata@nhs.net](mailto:bartshealth.bartsmsdata@nhs.net)**

Thank you for taking the time to read this information. If you have any comments or feedback about remote monitoring, please contact us at:

[bartshealth.bartsmsdata@nhs.net](mailto:bartshealth.bartsmsdata@nhs.net). Alternatively, you can telephone us: 0203 594 0637.

## References:

1. MS Society. What is MS? <https://www.mssociety.org.uk/about-ms/what-is-ms> (accessed 23, June 2023)
2. The MS Trust. (MS Decisions aid). <https://mstrust.org.uk/information-support/ms-drugs-treatments/ms-decisions-aid> (accessed July 2023)
3. MS Society. Disease Modifying Therapies Decision tool <https://www.mssociety.org.uk/about-ms/treatments-and-therapies/disease-modifying-therapies> (accessed June 2023)
4. Shift MS. <https://shift.ms/> (accessed June 2023)
5. CRIMSON Decision Aid [https://crimson.leeds.ac.uk/wp-content/uploads/sites/51/2020/12/CrimsonBrochure\\_WEB\\_2020-2.pdf](https://crimson.leeds.ac.uk/wp-content/uploads/sites/51/2020/12/CrimsonBrochure_WEB_2020-2.pdf) (accessed June 2023)
6. The ClinicSpeak. <https://clinicspeak.com/> (accessed June 2023)
7. MS Blog. <https://multiple-sclerosis-research.org/> (accessed June 2023)
8. MS selfie link: <https://ms-selfie.blog/> (accessed June 2023)

## Large print and other languages

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. For more information, speak to your clinical team.

এই তথ্যগুলো সহজে পড়া যায় অথবা বৃহৎ প্রিন্টের মত বিকল্প ফরম্যাটে পাওয়া যাবে, এবং অনুরোধে অন্য ভাষায়ও পাওয়া যেতে পারে। আরো তথ্যের জন্য আপনার ক্লিনিক্যাল টিমের সাথে কথা বলুন।

Na żądanie te informacje mogą zostać udostępnione w innych formatach, takich jak zapis większą czcionką lub łatwą do czytania, a także w innych językach. Aby uzyskać więcej informacji, porozmawiaj ze swoim zespołem specjalistów.

Macluumaadkaan waxaa loo heli karaa qaab kale, sida ugu akhrinta ugu fudud, ama far waa weyn, waxana laga yabaa in lagu heli luuqaado Kale, haddii la codsado. Wixii macluumaad dheeraad ah, kala hadal kooxda xarunta caafimaadka.

Bu bilgi, kolay okunurluk veya büyük baskılar gibi alternatif biçimlerde sunulabilir, ve talep üzerine Alternatif Dillerde sunulabilir. Daha fazla bilgi için klinik ekibinizle irtibata geçin.

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Please contact us if you need general information or advice about Trust services:  
[www.bartshealth.nhs.uk/pals](http://www.bartshealth.nhs.uk/pals)

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All our patient information leaflets are reviewed every three years.