Minimum MS service specification: For guidance during COVID-19 crisis

We recognise that these are far from ideal – or easy – times and that, as Neurologists, MS Nurses and AHPs you are all having to make some really tough decisions – not least about how to try and run the MS service you have spent so many years building up with far fewer hours than you would normally have available. We know that you are worried about your MS patients whilst many of you are also having to look after many other people who are very sick. We thank you for this and will do our best to support you in any way we can.

We have put together (in conjunction with some MS colleagues), a guide to the minimum service you should be aiming to provide for your patients. We have tried to suggest ways in which you can maintain the most essential aspects of your service so that you can keep yourselves and your patients safe and deliver the most urgent care in the most effective way. We hope that this will enable you to have positive discussions with your managers about continuing to staff the MS service during this crisis and will also help you (and us on your behalf) to manage patient expectations around the care MS services can provide during this period. Please remember that this is a guide rather than a mandate and if you are able to maintain your service at a higher level than the provision outlined here then you should continue to do so.

The chart below combines results from 5 UK MS teams who have recently run the patient survey administered by the MS Trust (NHS Lothian, Middlesbrough, NHS Lanarkshire, Bradford and Leicester). Respondents are asked what they would do if there was no MS nurse service and their response demonstrates the likely impact on A&E, GPs and Neurologists (respondents could give more than one answer). The recorded responses assume neurologists would be available if MS nurses were not and as this is not currently the case, the burden on A&E is likely to be much higher in the absence of any functioning MS service. It may be helpful to share this with Business Managers and Clinical Leads.

![Chart showing patient responses](chart.png)
We at the MS Trust are working hard to do all we can to help and support you and people with MS – we are updating the information on our website regularly and our enquiry line is fully staffed and busier than it has ever been. If you need help and support with specific local issues then contact us and of course you can always direct your patients to the MS Trust enquiry line or website if you are unable to provide them with advice yourself.

We remain, more than ever, committed to helping you keep your MS services going and to helping you continue to make a massive difference to the people in your care. If there is anything else that we can do to support you then please let us know.

We hope you find this helpful.

Thank you – keep safe,

All at the MS Trust
## MS Service specification guidance

<table>
<thead>
<tr>
<th>Point on pathway</th>
<th>Current Guidelines/Best Practice</th>
<th>Minimum service recommendation during pandemic</th>
</tr>
</thead>
</table>
| Newly diagnosed pwMS | Information provided at time of diagnosis and face to face follow up offered within 6 weeks – ideally with an MSSN¹ | • On receiving referral send a standard letter to people newly diagnosed explaining no face to face meetings at present and giving contact numbers for team if needed plus a list of relevant local resources and MS Trust/MS Society/Shift MS info and resources plus plan for future contact (copy to GP so they also have the information)  
• Provide a telephone appointment within 6 weeks from receiving referral after diagnosis with either an MSSN or MS AHP  
• Record and track newly diagnosed referrals received during this period and prioritise face to face appointments for this group once these are possible |
| Annual Reviews | Everyone should be offered a comprehensive annual review¹ | • Stop non-essential annual reviews – leave an answer phone message or communicate via letter/email to explain that all annual reviews will stop for the time being and that anyone with any concerns or issues relating to their MS should contact their team by email/telephone to request advice  
• Add the same information to the Out of office (OOO) facility on your team email so anyone contacting the service is updated as to what the team is able to offer and likely time lines; direct to other sources of information and available local resources |
<p>| Relapse/acute deterioration | Review and treat where appropriate within 2 weeks of onset¹ | • Should still aim to meet this standard but aim to assess majority of people over telephone/video call |</p>
<table>
<thead>
<tr>
<th>Task</th>
<th>Details</th>
</tr>
</thead>
</table>
| and work with local GPs re infection screen and prescriptions. | • Urgent patient queries should be responded to within no more than 2 working days  
• Only most serious should be seen face to face. Aim to avoid A&E attendance and admission wherever possible – review patients on infusion suite, treatment rooms or community clinics if running.  
• Home visits should be considered only where absolutely necessary and **only** if PPE is available.  
• Communicate with pwMS (answer phone message, email out of office) as to your new pathway and when pwMS should/should not contact centre. |
| Telephone service/email | PwMS should have a single point of access for the MS service with open access telephone line with messaging service and email access – all calls/emails should be returned within 2-3 working days. | • Answer phone message and out of office on team email should give clear information about how and when messages will be triaged and when it is likely a response can be expected – should also give advice on where to go in the meantime and ask people not to come to A&E unless there is no other option.  
• Consider who can triage calls and when; for example messages may be reviewed at beginning and end of each day by the MS admin/DMD coordinator – any urgent messages should be prioritised and responded to within 2 working days with the aim of preventing A&E visits/hospital admissions  
• Maintain or convert all clinics to telephone clinics but review who is booked in to ensure meeting needs of most vulnerable first (e.g. DMD monitoring, triaged calls, potential relapses etc.) |
| Symptom management | Face to face appointment/assessment leading to**:  
• MDT referral/support** | • All patient groups/meetings will be stopped for foreseeable future |
| DMD monitoring | As per SPC  
Mix of face to face and phlebotomy | Consider reducing frequency of monitoring in line with Covid-19 ABN guidelinesiii  
Provide monitoring via telephone clinics rather than face to face wherever possible  
Combine monitoring with infusion appointments whenever possible to reduce number of overall appointments  
Arrange phlebotomy remotely wherever possible – use pharma nurses wherever possible and this can be done safely for all concerned. |
|---|---|---|
| Initiation/Escalation/switch DMDs | As soon as possible | As soon as possible as per current ABN guidanceiv  
Provide or direct pwMS to information about use of DMDs during the pandemic e.g. ABN⁴ and MS Trust websitev |
| People with Advanced MS requiring proactive or maintenance care to preserve function and avoid admission | Home visits as required and annual comprehensive review \(^n\) | • Consider start/switch to DMDs with lower immunosuppressant action as per updated ABN guidance\(^4\)
• Use pharma nurses to train/support/facilitate switch wherever possible providing they have PPE available and are able to do so safely. Alternatively consider use of video conferencing to train patients remotely.
• Triage via telephone/video in response to contact
• Home visits should still be performed but only where essential and only if PPE provided - criteria for HVs should be primarily based on need for admission avoidance and those likely to come to significant harm without them
• Consider use of local, community based teams designed to prevent hospital admissions where available

| Communication | Proactive communication tailored to individuals and their specific needs | • Needs to be clear and consistent across all formats
• Ensure the out of office message on your team email and answer phone message all give information about how often messages will be checked, time frame in which pwMS can expect to receive a call back, alternative sources of help and what to do if they have an urgent MS query
• Encourage pwMS to be more proactive where possible and to take as much responsibility for their... |
own health as they can – direct to other resources such as MS Trust/MS Society/Shift MS but ensure they know who they should contact if they feel unwell.

With many thanks to:

Michelle Davies (MS Service Lead and Specialist Practitioner, Poole), Lou Jarrett (MS Clinical Nurse Specialist, Royal Devon and Exeter Hospital), Lindsay Lord (Advanced MS Champion, Manchester Centre for Clinical Neurosciences), Sylvia Lyons (MS Specialist Nurse, University Hospitals, Coventry), Michelle Meehan (MS Specialist Nurse, University Hospitals, Coventry) and Ruth Stross (MS Specialist Nurse, Central Surrey Health) for their comments and feedback and to Sarah White (Lead MS Clinical Nurse Specialist, St George’s University Hospitals) as Co-Chair of the UKMSSNA for her feedback and endorsement.

---

1 NICE Quality Standards for MS (2014) and General standards for neurological care and support (Scotland, 2019)
2 Evidence for MS Specialist Services (2015)
6 Improving services for people with Advanced MS (2016) MS Trust