

30 March 2020

MDS Advice letter – COVID-19 (coronavirus)
for MDS patients, carers, families and friends

Dear all,

This letter is mainly for those of you who can't access the internet. A copy of this advice is available on our website. This is also to explain that we compiled our Newsletter 11 **before** the full Covid-19 outbreak.

This is a special message and information to help you get through the next few months, in these difficult times of the coronavirus outbreak.

How are you coping? Do you have queries about how the coronavirus might impact your MDS care?

We know your care and treatment patterns may have been altered for your safety and to reduce the spread of the disease and understand why that may worry many of you.

First of all – some basic advice:

- All MDS patients are considered extremely vulnerable so **please stay at home** unless told otherwise by your clinical team (please keep following the NHS guidance for blood cancer).
- By now you should have received a letter from the NHS, with instructions for your ongoing care. Some MDS patients who are on "Watch & Wait" may not have received such a letter as their disease is considered stable. However, we advise **everyone** to stay at home.

Doctors and hospitals are adding more patients to the list of extremely vulnerable people, as not everyone has been identified yet. So do continue to follow advice for shielded patients. If you have not received a letter by Monday 30 March, contact your GP or clinical specialist for advice.

- **If you need general coronavirus assistance** (and have no support from family or friends, and no internet access) you can call: **Government Coronavirus support line** - Telephone: 0800 028 8327
- If you feel **unwell with COVID symptoms**, either call the hotline contact number for your clinical team if available, or access NHS 111 online, or call NHS 111.
- If you **are unwell for any other reason related to your MDS** then contact your haematology clinical team as you would normally. **DO NOT** attend hospital unless you are told to by the hospital staff.
- Try to stay calm, take control of your situation and make positive changes to prevent you or your loved ones from catching the virus. Our motto is "Keep calm, keep safe, keep corona away!"

Secondly – a SPECIAL REQUEST to you:

- We urge patients to **ask their families, friends, and colleagues to STAY AT HOME** – unless they are key workers. Together, if we all co-operate, we can drastically slow the spread of the virus.
- You can play your part and help from your home. Lead the way as, sadly, too many people are still not abiding by the advice and are endangering other citizens, as well as precious NHS staff.

This is the ONLY way to slow the spread down to a manageable situation.

- Help your NHS and all clinical staff who are working to save lives. If we all co-operate and act wisely, we can get through this.

Here are ways to get and give help:

Helpline: Tel 020 7733 7558 - now open 24/7

If you have a query, or are unclear about your MDS status, or feel distressed or anxious - please call us. We are working from home and the line is diverted to our mobile phone.

Mutual support and contact with others:

- **Online** - use our Facebook page and our online forum
- **Not online** – Call if you wish to act as a “Buddy” for those also seeking support by telephone. We will create a circle of support.
- **Smartphone only** - explore ways to make the most of it. Try checking our website or download the application WhatsApp to increase ways to communicate; use the video camera to speak to friends and family.
- **Local support groups** - we are exploring virtual patient meetings to help with the feeling of isolation – in every sense of the word. You can use your video camera to speak to one another. We will send out invitation emails soon.

International information:

We are working with our worldwide network of cancer patient advocates to bring you the best and latest advice. We are seeing a superb cooperation across the globe, supported by all MDS experts.

Blood donations:

We need you to **ask healthy friends and family to donate blood**, as there is now a shortage of blood reserves worldwide, due to the coronavirus. New volunteers are urgently needed to make up for the shortfall of people who are sick with Covid-19.

With all our international MDS colleagues, we have started a world-wide campaign for blood donations.

Without an increase in new donors, it will make it difficult for blood cancer patients to receive the same level of transfusions as usual.

This will worry many of you who are transfusion dependent – but rest assured clinical staff will keep your blood counts to a medically safe level at all times.

Some good news:

- **Treatment for Covid-19?**
Latest news talks about at least twelve compounds being researched.
- **Vaccine and mutations?**
Latest findings showing that the coronavirus is not mutating much. This means that a more permanent vaccine could be developed - just like - other immunisations such as those for measles, chickenpox, rubella etc. (This is unlike the flu immunisation, where the virus mutates regularly to overcome our immune system and therefore needs to be administered to people every year).
There are 44 vaccines currently being evaluated for possible use against covid-19, with two of them already at the clinical trial stage. But the path ahead is still very long.

There will be an end to this pandemic. The outbreak in China is now almost over, after 3 months, thanks to the strict measures of isolation and social distancing.

The same can happen in the UK and other countries **if** we all stay vigilant and all co-operate.

Please stay VERY safe. Take good care.

Sophie Wintrich
CEO, MDS UK

Guidance on shielding and protecting people defined on medical grounds as extremely vulnerable from COVID-19

Updated 24 March 2020

Background and scope of guidance

This guidance is for people, including children, who are at very high risk of severe illness from coronavirus (COVID-19) because of an underlying health condition, and for their family, friends and carers. It is intended for use in situations where the extremely vulnerable person is living in their own home, with or without additional support. This includes the extremely clinically vulnerable people living in long-term care facilities, either for the elderly or persons with special needs.

Shielding is a measure to protect people who are clinically extremely vulnerable by minimising all interaction between those who are extremely vulnerable and others. We are strongly advising people with serious underlying health conditions (listed below), which put them at very high risk of severe illness from coronavirus (COVID-19), to rigorously follow shielding measures in order to keep themselves safe.

What do we mean by extremely vulnerable? (MDS UK note: see MDS relevant areas in red)

People falling into this extremely vulnerable group include:

1. Solid organ transplant recipients.
2. People with specific cancers:
 - people with cancer who are undergoing active chemotherapy or radical radiotherapy for lung cancer
 - **people with cancers of the blood or bone marrow such as leukaemia, lymphoma or myeloma who are at any stage of treatment**
 - **people having immunotherapy or other continuing antibody treatments for cancer**
 - people having other targeted cancer treatments which can affect the immune system, such as protein kinase inhibitors or PARP inhibitors
 - **people who have had bone marrow or stem cell transplants in the last 6 months, or who are still taking immunosuppression drugs**
3. People with severe respiratory conditions including all cystic fibrosis, severe asthma and severe COPD.
4. People with rare diseases and inborn errors of metabolism that significantly increase the risk of infections (such as SCID, homozygous sickle cell).
5. **People on immunosuppression therapies sufficient to significantly increase risk of infection.**
6. Women who are pregnant with significant heart disease, congenital or acquired.

Shielding is for your personal protection. It is your choice to decide whether to follow the measures we advise. Individuals who have been given a prognosis of less than 6 months to live, and some others in special circumstances, could decide not to undertake shielding. This will be a deeply personal decision. We advise calling your GP or specialist to discuss this.

The NHS in England is directly contacting people with these conditions to provide further advice.

If you think you fall into one of the categories of extremely vulnerable people listed above and you have not received a letter by Sunday 29 March 2020 or been contacted by your GP, you should discuss your concerns with your GP or hospital clinician.

We understand this is an anxious time and people considered extremely vulnerable will understandably have questions and concerns. Plans are being readied to make sure you can rely on a wide range of help and support.

What you need to know

If you have an underlying health condition listed above, you are at very high risk of severe illness as a result of coronavirus (COVID-19) requiring admission to hospital.

Shielding is a practice used to protect extremely vulnerable people from coming into contact with coronavirus.

You are strongly advised to stay at home at all times and avoid any face-to-face contact for a period of at least 12 weeks from the day you receive your letter. Please note that this period of time could change.

Visits from people who provide essential support to you such as healthcare, personal support with your daily needs or social care should continue, but carers and care workers must stay away if they have any of the symptoms of coronavirus (COVID-19). You may find this guidance on [home care provision](#) useful. All people coming to your home should wash their hands with soap and water for at least 20 seconds on arrival to your house and often while they are there.

You should have an alternative list of people who can help you with your care if your main carer becomes unwell. You can also contact your local council for advice on how to access care.

If you think you have developed symptoms of COVID-19 such as a new, continuous cough or fever, seek clinical advice using the [NHS 111 online](#) coronavirus service or call NHS 111. Do this as soon as you get symptoms.

If you have someone else living with you, they are not required to adopt these protective shielding measures for themselves. They should do what they can to support you in shielding and they should stringently follow guidance on social distancing, reducing their contact outside the home. If you care for but don't actually live with someone who is extremely vulnerable, you should still stringently follow [guidance on social distancing](#).

How do these measures differ from the social distancing guidance for vulnerable people issued?

You are strongly advised to stay at home at all times and avoid any face-to-face contact for a period of at least 12 weeks from the day you receive your letter.

People who are not clinically extremely vulnerable who have contracted coronavirus (COVID-19) and recovered will be able to go about their normal business. If you are in this group we strongly advise that you should remain at home at all times.

Symptoms

The most common symptoms of coronavirus (COVID-19) are recent onset of:

- new continuous cough and/or
- high temperature (above 37.8 °C)

What is shielding?

Shielding is a measure to protect extremely vulnerable people by minimising interaction between those who are extremely vulnerable and others. This means that those who are extremely vulnerable should not leave their homes, and within their homes should minimise all non-essential contact with other members of their household. This is to protect those who are at very high risk of severe illness from coronavirus (COVID-19) from coming into contact with the virus.

If you think you have a condition which makes you extremely vulnerable or have received a letter from NHS England you are strongly advised to shield yourself, to reduce the chance of getting coronavirus (COVID-19) and follow the face-to-face distancing measures below.

The measures are:

1. Strictly avoid contact with someone who is displaying symptoms of coronavirus (COVID-19). These symptoms include high temperature and/or new and continuous cough.
2. Do not leave your house.
3. Do not attend any gatherings. This includes gatherings of friends and families in private spaces, for example, family homes, weddings and religious services.
4. Do not go out for shopping, leisure or travel and, when arranging food or medication deliveries, these should be left at the door to minimise contact.
5. Keep in touch using remote technology such as phone, internet, and social media.

Do use telephone or online services to contact your GP or other essential services.

We know that stopping these activities will be difficult. You should try to identify ways of staying in touch with others and participating in your normal activities remotely from your home. However, you must not participate in alternative activities if they involve any contact with other people.

This advice will be in place for at least 12 weeks from the day you receive your letter.

What should you do if you have someone else living with you?

While the rest of your household are not required to adopt these protective shielding measures for themselves, we would expect them to do what they can to support you in shielding and to stringently follow [guidance on social distancing](#).

1. Minimise as much as possible the time other family members spend in shared spaces such as kitchens, bathrooms and sitting areas, and keep shared spaces well ventilated.
2. Aim to keep 2 metres (3 steps) away from people you live with and encourage them to sleep in a different bed where possible. If you can, you should use a separate bathroom from the rest of the household. Make sure you use separate towels from the other people in your house, both for drying themselves after bathing or showering and for hand-hygiene purposes.
3. If you do share a toilet and bathroom with others, it is important that they are cleaned after use every time (for example, wiping surfaces you have come into contact with). Another tip is to consider drawing up a rota for bathing, with you using the facilities first.
4. If you share a kitchen with others, avoid using it while they are present. If you can, you should take your meals back to your room to eat. If you have one, use a dishwasher to clean and dry the family's used crockery and cutlery. If this is not possible, wash them using your usual washing up liquid and warm water and dry them thoroughly. If you are using your own utensils, remember to use a separate tea towel for drying these.
5. We understand that it will be difficult for some people to separate themselves from others at home. You should do your very best to follow this guidance and everyone in your household should regularly wash their hands, avoid touching their face, and clean frequently touched surfaces.

If the rest of your household stringently follow advice on social distancing and minimise the risk of spreading the virus within the home by following the advice above, there is no need for them to also shield alongside you.

Handwashing and respiratory hygiene

There are general principles you should follow to help prevent the spread of airway and chest infections caused by respiratory viruses, including:

- wash your hands more often - with soap and water for at least 20 seconds or use a hand sanitiser. Do this after you blow your nose, sneeze or cough, and after you eat or handle food
- avoid touching your eyes, nose, and mouth with unwashed hands
- avoid close contact with people who have symptoms
- cover your cough or sneeze with a tissue, then throw the tissue in a bin
- clean and disinfect frequently touched objects and surfaces in the home

What should you do if you develop symptoms of coronavirus (COVID-19)?

If you develop symptoms of COVID-19 (high temperature above 37.8 °C and/or new and continuous cough), seek clinical advice using the [NHS 111 online](#) coronavirus service or call NHS111 if you don't have internet access. In an emergency, call 999 if you are seriously ill. Do not visit the GP, pharmacy, urgent care centre or a hospital. Do this as soon as you get symptoms.

To help the NHS provide you with the best care if you need to go to hospital as a result of catching coronavirus, we ask that you prepare a single hospital bag. This should include your emergency contact, a list of the medications you take (including dose and frequency), any information on your planned care appointments and things you would need for an overnight stay (snacks, pyjamas, toothbrush, medication and so on). If you have an advanced care plan, please include that.

How can you get assistance with foods and medicines if you are shielding?

Ask family, friends and neighbours to support you and use online services. If this is not possible, then the public sector, business, charities and the general public are gearing up to help those advised to stay at home. Please discuss your daily needs during this period of staying at home with carers, family, friends, neighbours or local community groups to see how they can support you. Please visit gov.uk/coronavirus-extremely-vulnerable to register for the support that you need. This includes help with food, shopping deliveries and additional care you might need.

The government is helping pharmacies to deliver prescriptions. Prescriptions will continue to cover the same length of time as usual. If you do not currently have your prescriptions collected or delivered, you can arrange this by:

1. Asking someone who can pick up your prescription from the local pharmacy (this is the best option, if possible).
2. Contacting your pharmacy to ask them to help you find a volunteer (who will have been ID checked) or deliver it to you.

You may also need to arrange for collection or delivery of hospital specialist medication that is prescribed to you by your hospital care team.

If you receive support from health and social care organisations, for example, if you have care provided for you through the local authority or health care system, this will continue as normal. Your health or social care provider will be asked to take additional precautions to make sure that you are protected. The advice for formal carers is included in the [home care provision](#).

What should you do if you have hospital and GP appointments during this period?

We advise everyone to access medical assistance remotely, wherever possible. However, if you have a scheduled hospital or other medical appointment during this period, talk to your GP or specialist to ensure you continue to receive the care you need and determine which of these appointments are absolutely essential.

It is possible that your hospital may need to cancel or postpone some clinics and appointments. You should contact your hospital or clinic to confirm appointments.

What is the advice for visitors, including those who are providing care for you?

Contact regular visitors to your home, such as friends and family to let them know that you are shielding and that they should not visit you during this time unless they are providing essential care for you. Essential care includes things like help with washing, dressing or feeding.

If you receive regular health or social care from an organisation, either through your local authority or paid for by yourself, inform your care providers that you are shielding and agree a plan for continuing your care.

If you receive essential care from friends or family members, speak to your carers about extra precautions they can take to keep you safe. You may find this guidance on [home care provision](#) useful.

Speak to your carers about backup plans for your care in case your main carer is unwell and needs to self-isolate. If you need help with care but you're not sure who to contact, or if you do not have family or friends who can help you, you can contact your local council who will be able to help you and assess any social care needs you might have. Please visit gov.uk/coronavirus-extremely-vulnerable to register for the support that you need.

What is the advice for informal carers who provide care for someone who is extremely vulnerable?

If you are caring for someone who is extremely vulnerable due to severe illness from COVID-19, there are some simple steps that you can take to protect them and to reduce their risk at the current time. Ensure you follow advice on good hygiene:

- only care that is essential should be provided
- wash your hands on arrival and often, using soap and water for at least 20 seconds or use hand sanitiser
- cover your mouth and nose with a tissue or your sleeve (not your hands) when you cough or sneeze
- put used tissues in the bin immediately and wash your hands afterwards
- do not visit or provide care if you are unwell and make alternative arrangements for their care
- provide information on who they should call if they feel unwell, how to use NHS 111 online coronavirus service and leave the number for NHS 111 prominently displayed
- find out about different sources of support that could be used and accessing further advice on creating a contingency plan is available from [Carers UK](#)
- look after your own wellbeing and physical health during this time. Further information on this [is available](#).

How do you look after your mental wellbeing?

Social isolation, reduction in physical activity, unpredictability and changes in routine can all contribute to increasing stress. Many people including those without existing mental health needs may feel anxious about this impact including support with daily living, ongoing care arrangements with health providers, support with medication and changes in their daily routines.

If you are receiving services for your mental health, learning disability or autism and are worried about the impact of isolation please contact your key worker or care coordinator or provider to review your care plan. If you have additional needs please contact your key worker or care coordinator to develop a safety or crisis plan.

Understandably, you may find that shielding and distancing can be boring or frustrating. You may find your mood and feelings are affected and you may feel low, worried or have problems sleeping and you might miss being outside with other people.

At times like these, it can be easy to fall into unhealthy patterns of behaviour which in turn can make you feel worse. There are simple things you can do that may help, to stay mentally and physically active during this time such as:

- look for ideas of exercises you can do at home on the NHS website
- spend time doing things you enjoy – this might include reading, cooking, other indoor hobbies or listening to favourite radio programmes or watching TV
- try to eat healthy, well-balanced meals, drink enough water, exercise regularly, and try to avoid smoking, alcohol and drugs
- try spending time with the windows open to let in the fresh air, arranging space to sit and see a nice view (if possible) and get some natural sunlight, or get out into any private space, keeping at least 2 metres away from your neighbours and household members if you are sitting on your doorstep

Constantly watching the news can make you feel more worried. If you think it is affecting you, try to limit the time you spend watching, reading, or listening to media coverage of the outbreak. It may help to only check the news at set times or limit this to a couple of times a day.

Try to focus on the things you can control, such as your behaviour, who you speak to and who you get information from. [Every Mind Matters](#) provides simple tips and advice to start taking better care of your mental health.

If you are struggling with your mental health, please see the NHS mental health and wellbeing advice website for self-assessment, audio guides and tools that you can use. If you are still struggling after several weeks and it is affecting your daily life, please contact [NHS 111 online](#). If you have no internet access, you should call NHS 111.

What steps can you take to stay connected with family and friends during this time?

Draw on support you might have through your friends, family and other networks during this time. Try to stay in touch with those around you over the phone, by post or online. Let people know how you would like to stay in touch and build that into your routine. This is also important in looking after your mental wellbeing and you may find it helpful to talk to them about how you are feeling if you want to.

Remember, it is okay to share your concerns with others you trust and in doing so you may end up providing support to them, too. Or you might want to try an [NHS recommended helpline](#).

What is the advice for people living in long-term care facilities, either for the elderly or persons with special needs?

The advice also applies to extremely vulnerable persons living in long-term care facilities. Care providers should carefully discuss this advice with the families, carers and specialist doctors caring for such persons to ensure this guidance is strictly adhered to.

What is the advice for parents and schools with extremely vulnerable children?

The advice also applies to extremely vulnerable children in mainstream and special schools.



International MDS Alliance Information

Webinar - Bone Marrow Failure and the Coronavirus (COVID-19):

15 Frequently Asked Questions

Transcribed from the AAMDSIF webinar on March 13, 2020 with Dr. Mikkael Sekeres and Dr. Isabel Schuermeyer with the Cleveland Clinic, edited for clarity and brevity.

Thanks to our colleagues from AAMDSIF for sharing this with us.

1) Is there a difference between the susceptibility to the coronavirus of patients with bone marrow failure and those who do not have bone marrow failure?

A: Bone marrow failure patients are more susceptible to infections in general, however this has not been studied enough. The reason we are focused so much on elders and people with compromised immune systems is that, if they catch the virus, it can be much more serious because they don't have the defences to get rid of it.

2) Is there a different risk for MDS, high risk versus low risk?

A: High risk tends in general to have a more comprised immune function than low risk, so I would think that it would be slightly higher risk, but I've seen low risk folks who have impaired immune function. I've seen high risk folks who have preserved immune function.

3) Is it known which blood cells will attack viruses in general and is this the same for the coronavirus?

A: The lymphocytes are the ones that attack viral infections, but they all work together. So to simply answer your question, it's the lymphocytes; the more complicated answer to your question is that all of our white blood cell elements work as a team to fight all sorts of infections.

4) What is the impact of COVID-19 on bone marrow failure patients who are getting active treatment? What should they do?

A: If you have a scheduled treatment, don't skip that treatment. You still need to get treated for your bone marrow condition. If it's an every six month follow-up or every three month follow-up, call your doctor's office and see if the appointment is really necessary or if it can be rescheduled until the active infection cycle has passed. Your medical centre may allow you to participate in a virtual visit from your home.

5) What about medications?

A: Make sure that you have a three month supply of your medication available, and possibly arrange mail order delivery of your medications.

6) Do you have any recommendations for any type of special cleaning of fruits, vegetables, and other un-packaged foods from the grocery store?

A: Normal washing protocol for fruits and vegetables – a good rule here is the same 20 second minimum for hand washing.

7) Our father is 70, high risk MDS, and is due to start a course of EPO injections, are there any additional considerations that need to be given with the virus?

A: No more special considerations than trying to prevent getting infected with the virus. Ask how urgent it is to get started on treatment. If someone has higher risk MDS, it might be urgent to get that under control where someone with low risk MDS could wait for four weeks.



8) I had a transplant a few years ago and have normal blood values, would I still consider myself high risk or just take precautions as a healthy adult?

A: I would think transplant, even though you're out of the real danger period for when you're under super duper precautions, the first 100 days, the first six months, the first year post-transplant, I would still consider you high risk. I don't know enough about your personal situation to know if you have graft versus host disease or if you're still on some degree -of MDS suppressants. So I would err on the side of caution, consider yourself high risk.

9) My husband is having a bone marrow transplant in the next few weeks. Do you have any suggestions on how to proceed and what types of questions we should ask before making the decision to move forward?

A: Check in with your transplant centres and ask what they're doing about this virus and if they're screening patients beforehand. Many people can't wait for a bone marrow transplant. You have something that is severely compromising your bone marrow function, and transplant represents a potential chance of cure, you've been waiting months to get to this point to finally get to the transplant and then this virus hits. So I think some transplants centres are formally testing people before they go through with the transplant, others are assessing your symptoms and if you don't have the symptoms, they're giving you the go ahead for transplant.

10) Would it be helpful in any way for patients to receive a pneumonia shot?

A: Yes, if you're due for one.

11) Is there any danger of running out of blood supplies?

A: There is a danger of a shortage.

UPDATE FROM AAMDSIF: Please refer to this briefing from the Red Cross on the national blood shortage: <https://www.redcrossblood.org/local-homepage/news/article/critical-bloodshortage-3A-red-cross-urges-blood-and-platelet-donors-to-give-now-1.html>

12) Do you have any advice for newly diagnosed patients who maybe have not started treatment yet for MDS? Would it be safe for them to start treatment?

A: It depends on the treatment you're getting. If you have a lower risk myelodysplastic syndrome and you're starting treatment with an erythropoiesis-stimulating agent like Procrit or Aranesp, go ahead and start the treatment. This isn't going to affect it at all. If, on the other hand, you're starting a treatment that may lower your white blood cell count, then I would check with your doctor about how important it is that you start that therapy right now as opposed to waiting a month or two.

13) Are there any extra supplement that patients can use to boost their immune system?

A: No. That's a hard no.

14) What are the initial symptoms of the virus? Is it possible to have the virus without a fever?

A: Anything is possible. So the most common symptoms are fever, sore throat, and cough, but the virus can be transmitted without any symptoms at all for about five days. The one thing that doesn't seem to be associated with it is all the kind of stuffy nose, sneezing, runny nose that we associate with a lot of other viruses. Doesn't mean it can't get that, it's just less common. So your suspicion that it's the coronavirus should be higher in the setting of fever, cough and sore throat.

15) Are support groups helpful for patients during this time? Are there any other resources for connecting with patients for support?

A: I do think support groups can be helpful, although I would suggest that they be done virtually.

MDS UK Note: the following document was created by the **UK MDS Forum**, the UK group of MDS experts, to assist all haematologists treating MDS in the UK during the Covid pandemic. Please feel free to refer to it during consultations with your haematologist. Any queries, please contact our MDS UK Helpline.



UK MDS Forum guidance during COVID-19 outbreak

COVID-19 virus is highly infectious and produces severe life-threatening pneumonia. The epidemiology is becoming clearer, resulting in the definition of patient groups at highest risk for severe disease. The general advice on Patient Support websites should be followed:

<https://mdspatientsupport.org.uk/coronavirus-mds-blood-cancer-advice/>

The rapid guidance from NICE for systemic anti-cancer therapy in the COVID-19 outbreak should be followed:

<https://www.nice.org.uk/guidance/ng161>

The UK MDS Forum proposes the following more specific guidance for the interventional management of MDS patients during the period of highest risk from infection with COVID-19. There is a limited (or no clear) evidence base for the majority of these recommendations which are practical and consensus in this unprecedented time of crisis.

Hypomethylating agents - azacitidine

New diagnoses of IPSS INT-2/High patients

- Almost all patients will become neutropenic during the first 1-3 cycles of azacitidine therapy
- Therefore consider whether a delay in initiating azacitidine could be acceptable to the patient and clinician. In the AZA-001 registration study, only 52% patients were treated within one year of original diagnosis (which for some may have been lower-risk). Patients' management should be assessed by the MDT on an individual basis and then discussed with the patient. Delay may be acceptable for the following groups but this is not an exhaustive list:
 - Patients with relatively well preserved blood counts (e.g. neutrophils >1)
 - Patients with stable blood counts for the preceding 3 months and neutrophils > 1
 - Patients with lower blast count (<10%)
 - Patients lacking good-risk 'AML' genetic / genomic characteristics
- If azacitidine therapy deemed immediately necessary, consider using G-CSF and / or antibiotic prophylaxis through cycles 1 & 2 in order to try to prevent hospitalisation with neutropenic sepsis.
 - Where feasible and subject to local guidelines for home administration of azacitidine, consider alternative models of care to minimise hospital attendance for azacitidine injections
 - Blood count monitoring should not be reduced, continuing per local guidelines, but samples taken in the patient's home where possible and attendance to hospital following, based on local blood product transfusion policy.

Patients already on azacitidine

- Beyond cycle 3, if patients are deemed to be having clinical benefit, consider increasing interval between cycles to 6 weeks, or continuing 4-weekly but reduce to 5 days azacitidine per cycle. Note that there is no trial evidence for a switch from 4-weekly to 6-weekly intervals, but there is some (under-powered) randomised trial evidence that 5-day azacitidine cycles may be less efficacious than 7-day cycles.

Lenalidomide

- For newly diagnosed patients with isolated del(5q) MDS who may be candidates for lenalidomide therapy, defer therapy and continue transfusional support
- For responding patients established on lenalidomide, continue therapy

Intensive chemotherapy

- No generalised guidance can be provided other than to suggest an individual patient risk versus benefit assessment for delaying intensive therapy or considering alternative lower intensity therapy in the light of likely greater risk of treatment related mortality from COVID-19 infection after intensive chemotherapy.

Allogeneic stem cell transplantation

- Again no generalised guidance can be provided other than to suggest an individual patient risk versus benefit assessment for delaying stem cell transplant in the light of likely greater risk of treatment related mortality from COVID-19 infection

G-CSF

- Patients with profound neutropenia and recurrent infection may temporarily be candidates for G-CSF provided this can be self-administered and does not increase attendance to hospital.

Transfusion

- In an attempt to reduce hospital attendance all transfusion-dependent patients should be reviewed to assess if increased intervals between transfusions is possible without significant medical risk.

Writing group: UK MDS Forum and NCRI MDS subgroup. Clinicians can contact any member of these working groups for further advice if required, or:

Prof David Bowen, Lead for Writing Group, Leeds
Dr Sally Killick, NCRI MDS chair, Bournemouth
Dr. Dominic Culligan, UK MDS Forum Chair, Aberdeen

This is a set of consensus recommendations created to bridge the unprecedented burden that the COVID-19 pandemic is placing on the NHS. The guidance will be reviewed at the end of May 2020 and will expire when the COVID-19 infection is deemed to no longer be clinically significant for MDS patients.