Azacitidine for myelodysplastic syndromes, chronic myelomonocytic leukaemia and acute myeloid leukaemia

This leaflet is about when azacitidine should be used to treat people with myelodysplastic syndromes, chronic myelomonocytic leukaemia and acute myeloid leukaemia in the NHS in England and Wales. It explains guidance (advice) from NICE (the National Institute for Health and Clinical Excellence). It is written for people with myelodysplastic syndromes, chronic myelomonocytic leukaemia and acute myeloid leukaemia but it may also be useful for their families or carers or for anyone with an interest in the condition.

It does not describe myelodysplastic syndromes, chronic myelomonocytic leukaemia and acute myeloid leukaemia or the treatments in detail – a member of your healthcare team should discuss these with you. You can get more information from the organisations listed on the back page.
This may not be the only possible treatment for myelodysplastic syndromes, chronic myelomonocytic leukaemia and acute myeloid leukaemia. Your healthcare team should talk to you about whether it is suitable for you and about other treatment options available.

What has NICE said?
NICE recommends azacitidine as a possible treatment for some adults with myelodysplastic syndromes, chronic myelomonocytic leukaemia or acute myeloid leukaemia.

Who can have azacitidine?
People who cannot have a stem cell transplant may be able to have azacitidine. Azacitidine is ‘licensed’ (approved as being safe by the European regulatory agency) for adults with myelodysplastic syndromes, chronic myelomonocytic leukaemia or acute myeloid leukaemia, but only in specific circumstances, for example, depending on the characteristics of the person’s blood and bone marrow. You should talk to your doctor to find out if you are able to have this treatment.

Why has NICE said this?
NICE looks at how well treatments work, and also at how well they work in relation to how much they cost the NHS. NICE applies special considerations to treatments that can extend the lives of people who are nearing the end of their life. NICE recommended azacitidine because the cost is justified by the benefits it provides when the special considerations are applied.

Myelodysplastic syndromes, chronic myelomonocytic leukaemia and acute myeloid leukaemia
Myelodysplastic syndromes are conditions in which the bone marrow does not produce enough healthy blood cells. In chronic myelomonocytic leukaemia and acute myeloid leukaemia the bone marrow makes too many white blood cells that are not fully developed and are not able to work normally.
Azacitidiné
Azacitidiné (also known as Vidaza) is a chemotherapy drug. It interferes with the growth of cancer cells and destroys them. Azacitidiné also helps the bone marrow to produce normal blood cells. It is given by injection.

What does this mean for me?
When NICE recommends a treatment, the NHS must make sure it is available to those people it could help, normally within 3 months of the guidance being issued.

So, if you have myelodysplastic syndromes, chronic myelomonocytic leukaemia or acute myeloid leukaemia, and you and your doctor think that azacitidiné is the right treatment for you (see ‘What has NICE said?’ across the page), you should be able to have the treatment on the NHS. Please see www.nice.org.uk/aboutguidance if you think you are eligible for the treatment but it is not available.
More information

The organisations below can provide more information and support for people with myelodysplastic syndromes, chronic myelomonocytic leukaemia and acute myeloid leukaemia. NICE is not responsible for the quality or accuracy of any information or advice provided by these organisations.

- CancerHelp UK (the patient information website of Cancer Research UK)
  0808 800 4040
  www.cancerhelp.org.uk
- Leukaemia CARE, 0808 801 0444
  www.leukaemiacare.org.uk
- Macmillan Cancer Support, 0808 808 0000
  www.macmillan.org.uk
- MDS UK Patient Support Group, 020 7733 7558
  www.mdspatientsupport.org.uk
- Rarer Cancers Forum, 0800 434 6476
  www.rarercancers.org.uk

NHS Choices (www.nhs.uk) may be a good place to find out more. Your local patient advice and liaison service (usually known as ‘PALS’) may be able to give you more information and support. If you live in Wales you should speak to NHS Direct Wales for information on who to contact.

About NICE

NICE produces guidance (advice) for the NHS about preventing, diagnosing and treating medical conditions. The guidance is written by independent experts, including healthcare professionals and people representing patients and carers. They consider the evidence on the disease and treatments, the views of patients and carers and the experiences of doctors, nurses and other healthcare professionals, and consider the costs involved. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

This leaflet and other versions of the guidance aimed at healthcare professionals are available at www.nice.org.uk/guidance/TA218

You can order printed copies of this leaflet from NICE publications (phone 0845 003 7783 or email publications@nice.org.uk and quote reference N2492). The NICE website has a screen reader service called Browsealoud, which allows you to listen to our guidance. Click on the Browsealoud logo on the NICE website to use this service.

We encourage NHS and voluntary organisations to use text from this leaflet in their own information about myelodysplastic syndromes, chronic myelomonocytic leukaemia and acute myeloid leukaemia.