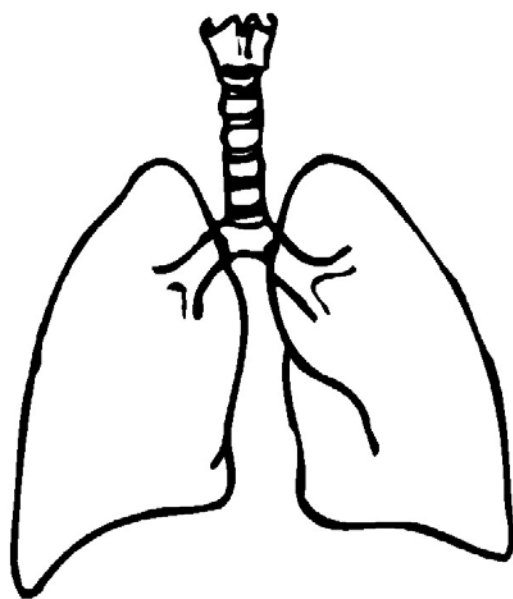


Accessing Pemetrexed Disodium (Alimta)

Advice on how to campaign for access
to Pemetrexed Disodium



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Introduction

This pack has been put together to help people who have been diagnosed with malignant pleural mesothelioma and who want to gain access to the chemotherapy drug pemetrexed Disodium (also known as Alimta).

Treatment with Pemetrexed Disodium is not appropriate for all mesothelioma patients. It is not a cure for mesothelioma, but it can extend life and also, importantly, alleviate symptoms for some patients. Before you challenge your health care providers, known as the primary care trust (PCT), about funding for Pemetrexed discuss your chemotherapy options with your oncologist. He or she can advise whether chemotherapy is an option for you and which drug treatments are appropriate. You must then decide if chemotherapy is something you want to have.

The current situation

Chemotherapy was available to mesothelioma patients before Pemetrexed Disodium became the 1st licensed drug in the UK for this purpose in November 2004. It is common practice, where licensed drugs are lacking, to use existing chemotherapy drugs 'off license'. This happens in the treatment of many diseases and continues in the treatment of mesothelioma.

In early 2005, NICE started to consider whether to recommend Pemetrexed Disodium for the treatment of Malignant Pleural Mesothelioma in a process known as a technology appraisal. The initial decision by NICE not to recommend the treatment was appealed twice and in July 2007, NICE issued their Final Appraisal Determination (FAD). The FAD adhered to the evidence generated by the research involving Pemetrexed Disodium in that they recommended its use only in non-surgical patients who have not received any previous chemotherapy. However this decision too was appealed against causing further delay and access to the treatment.

There are two possible outcomes to this latest appeal :

1. The appeal is rejected but PCT will still be able take full advantage of the 90 day lead in period, in which case, the earliest date for access to Pemetrexed Disodium will be in May 2008;
2. The appeal is upheld and the full appraisal process has to be repeated, in which case, providing that the eventual decision is to fund

Pemetrexed Disodium the earliest date for accessing it will be in October/November 2008.

Pemetrexed Disodium has been freely available in Scotland since July 2005, following advice from the Scottish Medicines Consortium (SMC) and in most of the developed world. Only a handful of PCT's across England have continued to fund treatment with Pemetrexed Disodium for mesothelioma patients despite Department of Health guidelines which make it clear to PCTs that simply waiting for NICE is not an option.

The Department of Health

In December 2006, the Department of Health published best practice guidance on the issue of access to medicines which are currently being reviewed by NICE. It stated:

"It is not acceptable to cite lack of NICE guidance as a reason for not providing a treatment...the NHS will have to continue to make informed decisions about the use of these interventions."

To help make informed decisions the circular refers to other respected appraisal bodies such as the Scottish Medicines Consortium (SMC) and the London Cancer New Drugs Group. Both of these have endorsed Pemetrexed Disodium for mesothelioma. None of the others listed have stated a view.

The Department of Health document also says:

"Each PCT should use its best endeavours to ensure that any new treatments recommended by NICE are available as soon as possible after NICE issues Technology Appraisal Guidance. If it is possible for a PCT to make necessary arrangements without utilising the full three month period stipulated in the Directions, it should do so."

These two recommendations should be taken into consideration by a PCT who are making a decision either before NICE guidance is issued or immediately after guidance has been issued which recommends the treatment.

Submitting an application for Pemetrexed Disodium

Checking with your Primary Care Trust (PCT)

Having checked with your oncologist that treatment with Pemetrexed Disodium is appropriate for you find out whether your PCT will fund Pemetrexed Disodium. Your GP or oncologist will be able to tell you or you can contact your PCT directly. If you do not know your PCT, ask at your local health centre or doctor's surgery.

If your PCT does not fund Pemetrexed Disodium your oncologist will make an individual application for treatment. Your application should be heard very quickly and if your PCT turns down your application you can appeal. **Submitting an Appeal against a PCT decision not to fund treatment.**

How?

Each PCT has its own appeals process so you need to find out from them what the process is. Ask for:

- A written copy of the process so you have a record
- The criteria the PCT uses to assess the appeal
- A list of documents they need for the appeal meeting
- The deadline to submit an appeal

Who?

In some cases it is the patient who appeals and in others their doctor appeals for them. Whatever rules apply, your oncologist should support your appeal and send a letter of appeal. In addition, if you are too ill to pursue the appeal yourself you can nominate someone to act on your behalf. You should provide written confirmation to the PCT with your application that you have nominated this person to act for you.

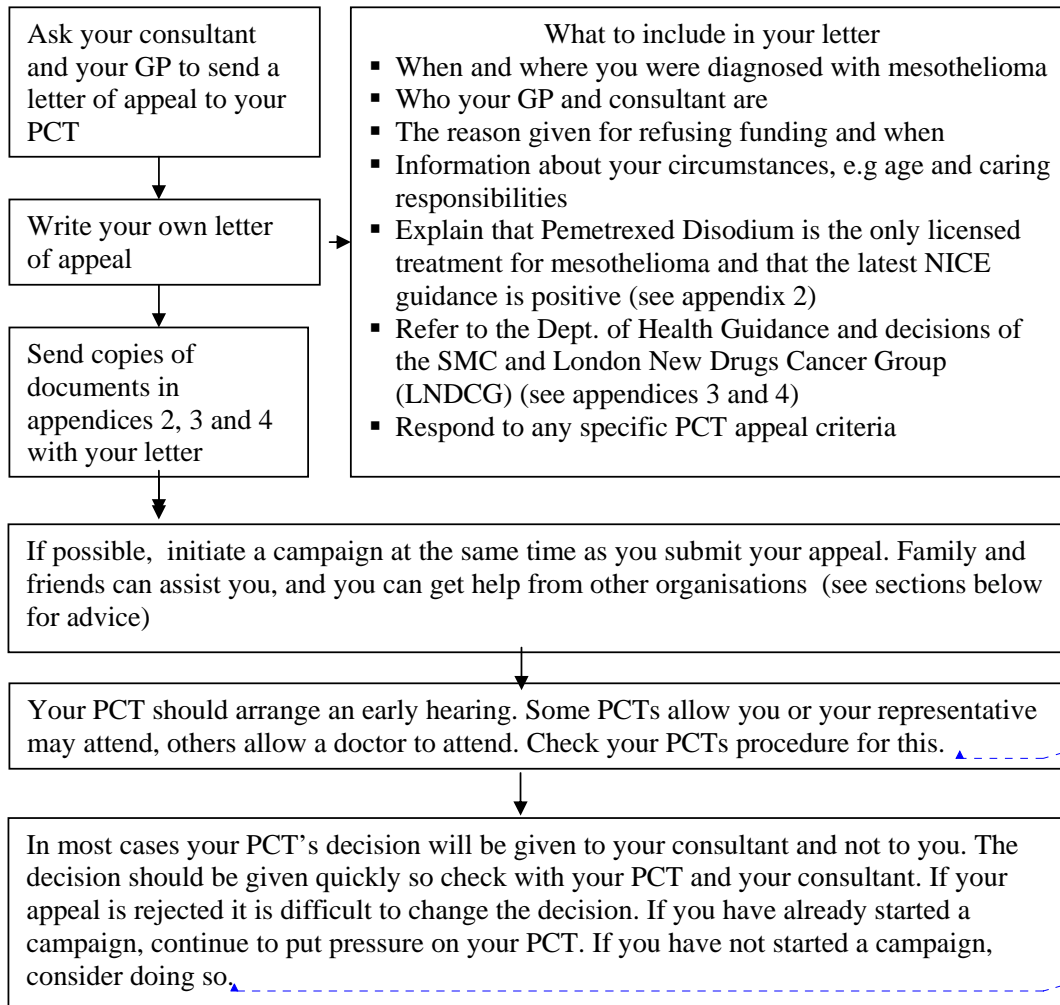
When?

Make your application as soon as you can. You may have to wait for a response from the PCT so save what time you can by applying quickly. Don't worry if you get the list of criteria after you have already sent your letter in. You can send a second letter which will be used as long as it gets to the PCT before the appeal date.

Involving others

If possible, get support for your appeal from your MP, friends and family and the media. While your appeal is being processed it is important that your PCT is aware of the wider concerns about the postcode lottery that affects mesothelioma sufferers. Campaigning in this way is not for everyone, but you should give it serious consideration. If this is something you feel able to do, please look at the advice in the section below, '*Getting help to appeal*' ,

The appeal process



Getting help to appeal

Charities and Patient Support Groups

You have probably been given this pack or downloaded it from the websites of an Asbestos Victim Support Group or Mesothelioma UK. These organisations support people with mesothelioma and their families. They have experience of helping people appeal to gain funding for Pemetrexed Disodium and can give you advice and practical support. Please call to talk about your situation and they will offer what support they can.

Asbestos Victims Support Groups Forum UK

Contact: Tony Whitston, Greater Manchester Asbestos Victims Support Group,

Tel: 0161 636 7555; Mobile: 077 48189 837.

Website: <http://www.asbestosforum.org>

Mesothelioma UK

Mesothelioma UK: National Macmillan Mesothelioma Resource Centre
Provides expert, impartial, up-to-date information on mesothelioma to patients and carers

Helpline: 0800 169 2409

E Mail: mesothelioma.uk@uhl-tr.nhs.uk

Website: www.mesothelioma.uk.com

Regional Asbestos Victims Support Groups and members of the Forum

Regional group	Telephone	Address	Email and website
Greater Manchester Asbestos Victims Support Group	0161 636 7555 Contact: Tony Whitston	Windrush Millenium Centre Unit 2.5, 70 Alexandra Road Moss Side, Manchester M16 7WD	asbestos.gmavsg@virgin.net www.asbestos-victims-support.org
Asbestos Awareness Wales	Tel: 07775 815 705	20b Marine Parade Penarth, Vale of Glamorgan	asbestosawarenesswales@yahoo.co.uk
Barking & Dagenham Asbestos Victims Support Group	0207 794 5999	Hampstead Town Hall Centre 213 Haverstock Hill London NW3 4QP	mail@lhc.org.uk http://www.badasbestos.org.uk/
Barrow Asbestos-Related Disease Support	Tel: 01229 580305 Fax: 01229 583072	St Mary's Hospice, Ford Park, Ulverston, Cumbria, LA12 7JP	info@stmaryshospice.org www.stmaryshospice.org
Bradford Asbestos Victims Support Group	Tel: 01274 393949 Fax: 01274 393949 Contact: Carol Duerden	UNISON Offices, 2nd Floor, Auburn House Upper Piccadilly, Bradford BD1 3NU	hazards@what-bohp.freemove.co.uk
Cheshire Asbestos Victims	Tel: 01928 576641 Fax: 01928 576649	3 Fryer Street, Runcorn, Cheshire, WA7 1ND	cavsg@btconnect.com www.cavsg.co.uk

Support Group	Contact: Brian Delaway		
Derbyshire Asbestos Support Team	<i>Tel: 0124 623 1441</i> <i>Fax: 0124 655 1529</i> Contact: Joane Carlin	Trade Union Safety Team 70 Saltergate Chesterfield, Derbyshire S40 1JR	mail@asbestos.support.co.uk http://www.asbestosupport.co.uk
Hampshire Asbestos Support & Awareness Group (HASAG)	Tel: 0779 254 3426 Contact: Diane McLellan Tel: 0794 032 8637 Contact: Lynne Squibb	13 Wychwood Grove, Chandlers Ford, Eastleigh SO53 1FQ	diane@hasag.co.uk or lynne@hasag.co.uk www.hasag.co.uk
Merseyside Asbestos Victims Support Group	<i>Tel: 0151 236 1895</i> <i>Fax: 0151 236 1895</i> Contact: John Flanagan	Unit 3, Oriel Close, Water St, Liverpool L2 8UQ	gfr15@dial.pipex.com www.asbestosdiseases.org.uk
Mick Knighton Mesothelioma Research Fund	Contact Mrs Chris Knighton direct: Telephone 0191 2637386	The Mick Knighton Mesothelioma Research Fund C/O. The British Lung Foundation Sir G.B Hunter Memorial Hospital, The Green, Wallsend, Tyne and Wear NE28 7PB	chrisknighton@mkmrf.freemove.co.uk
Northeast Asbestos Support & Awareness Group	<i>01642 240044</i> Contact: Bob Stephenson	Trade Union Centre 119/121 Marton Road, Middlesborough, TS1 2DU	information@nasag.org.uk www.nasag.org.uk
Ridings Asbestos Support & Awareness Group	<i>0113 231 1010</i> Contact: Tom Carden	50B Armley Town Street Armley, Leeds LS12 3AA	information@asbestos-action.org.uk http://www.asbestos-action.org.uk
Sheffield and Rotherham Asbestos Group	<i>0114 282 3212</i> Contact: Paula Walker	Unit 311, Aizlewood's Mill, Nursery St, Sheffield S3 8GG	sarag@aizlewoodsmill.co.uk
North West Wales Asbestos Victims Support Group	<i>Tel 1: 0176 652 2238</i> <i>Tel 2: 0176 677 0546</i> Contact: Sid Caplan	19 Lon Dinas Cricieth, Gwynedd LL52 0EH	

Contacting your MP

It is part of your Member of Parliament's role to support people in their constituency who need help to resolve an issue. Many MPs have expressed an interest in mesothelioma and the issues that have surrounded treatment and compensation. They can support you by:

- Writing directly to your PCT, Cancer Network and Strategic Health Authority
- Raising your case in the House of Commons
- Adding their voice to any media coverage you get

If you do not know who your MP is you can find out by entering your postcode at <http://www.upmystreet.com/commons/>

It is a good idea to contact your MP's office and try and make an appointment to see him/her in person. MPs hold surgeries in their constituencies on a Monday and/or Friday. You should be able to take someone with you and it's worth writing down some details to leave with your MP: about your illness and the treatment you need, any key dates coming up such as an appeal hearing and details of any media campaigning you may be involved in (see below).

Many MPs have taken an interest in the issue of mesothelioma and some have signed up to one of several 'Early Day Motions' (EDM) to voice their support. Ask your MP to sign EDM 221. If you want to see if your MP has done so, you can look online at

EDM 221 – Mesothelioma and NICE Appraisal Procedure

<http://edmi.parliament.uk/EDMi/EDMDetails.aspx?EDMID=34323&SESSION=891>

<http://edmi.parliament.uk/EDMi/EDMDetails.aspx?EDMID=32805&SESSION=885>

<http://edmi.parliament.uk/EDMi/EDMDetails.aspx?EDMID=32934&SESSION=885>

You can write to your MP at:

Name of MP

House of Commons

London

SW1A 0AA

All MP's offices can be contacted by calling 020 7219 3000.

Contacting the Media

Press campaigns run by mesothelioma patients, and their family and friends, can create pressure on a PCT to explain the evidence base for their decision and be held accountable to the local people they serve. In the past, campaigns have also been successful in changing PCT policy on

funding treatment for mesothelioma. There is an example of such a case in appendix 3 below.

Not everyone feels comfortable with discussing their situation in public so getting the media involved is not for everyone. However, it can make a big difference to your campaign. The following tips can make the process less daunting:

- Before you speak with the media write a short summary about your illness with dates for key events like diagnosis, PCT appeal etc
- Ask your GP, oncologist and patient support group if they are happy to comment
- Ask close members of your family if they would be willing to be interviewed too
- Talk to someone else who has launched a similar campaign. The Asbestos Victim Support Group Forum or Mesothelioma UK will be able to put you in touch with a mesothelioma patient who has had experience of talking to the media about the disease and treatment.

How to do it

Local and regional media are interested in local stories so they are the best people to contact. To find out about your regional newspapers, radio and TV stations ask the Asbestos Victims Support Groups or Mesothelioma UK or you can use www.mediauk.com - just key in the location into the search box. When you contact the media, ask to speak to the health editor. Explain you are a cancer patient who has been denied the only licensed treatment for your condition by your PCT. The journalist will ask you more questions if they are interested and may set up an interview with you. Ask questions so that you are clear about what any interviews will involve. Keep a note of the arrangements.

Interviews

- Rehearse what you want to say: why you want Pemetrexed Disodium, why you haven't been able to get it and what difference it could make to you and your family
- Find out if other local PCTs fund it and make the point that you are the victim of the postcode lottery that currently prevails in the UK. The medicine is routinely available in North East and North West England and in Scotland.
- Ask the journalist how long the interview will last, what they will ask you and for radio or television if it is live or recorded (live interviews tend to be very short. With a pre-recorded interview you can answer a question again if you weren't happy with your first answer)

- Remember the media are interested in your story and will be sympathetic
- Speak clearly and slowly and keep your answers fairly brief
- Ask for a copy of any finished article, TV or radio item.

Contacting the Healthcare Commission

The Healthcare Commission is an independent body responsible for reviewing complaints about the NHS in England, that haven't been resolved at a local level. If your PCT will not uphold your appeal, you can ask the Healthcare Commission for an 'Independent Review' of your case. You need to make sure that you state you are a priority case and the Commission will take this into account and deal with your case as quickly as possible. This may still take a number of weeks.

You can request a form from their website and should include all the information regarding your appeal to the PCT.

Contact details

Tel: 0845 601 3012

Email: complaints@healthcarecommission.org.uk

Website:

<http://www.healthcarecommission.org.uk/aboutus/complaints.cfm>

Other useful contact details

Justice for Asbestos Victims North West

12 Elaghmore Park

Londonderry BT4 88DX

Tel: 028 7135 2090

Justice for Asbestos Victims

523 Antrim Road, Belfast BT15 3BS

Tel: 028 9078 3923

Email : jav_ire@hotmail.com

Macmillan Cancer Relief: Specialist care for people with cancer. Tel: 020 78407840

Clydeside Action on Asbestos

245 High Street, Glasgow G4 0QR

Tel: 0800 587 7517

Clydebank Asbestos Group

8 Crown Avenue, Radnor Park, CLYDEBANK G81 3BW

Tel: 0141 951 1008

Email: clydebankasbestos@ntlbusiness.com

Asbestos Action Tayside
Tel: 01592 261403
Email: ianbabbs@asbestosactiontayside.org.uk

Cancerbackup: National charity providing information and counselling for people with cancer. Cancer Information Service Mon-Fri 9.00 to 19.00.
Tel: 08088001234

Cancerlink: Cancer information helpline
Tel: 0800 132 905
Asian helpline 0800 590 415

National Institute for Health and Clinical Excellence
MidCity Place, 71 High Holborn
London WC1V 6NA
Tel: +44 (0) 20 7067 5800
Email: nice@nice.org.uk
Website: <http://www.nice.org.uk/>

Secretary of State for Health
The Department of Health
Richmond House, 79 Whitehall
London SW1A 2NS
Tel: 020 7210 4850
Email: dhmail@dh.gsi.gov.uk
Website: <http://www.dh.gov.uk/en/index.htm>

Trades Union Congress
Congress House, Great Russell Street, London WC1B 3LS
Tel: 020 7636 4030
www.tuc.org.uk

Appendices

Appendix 1: FAD

Appendix 2: DoH statement

Appendix 3: SMC

Appendix 4: London Cancer New Drugs Group

Appendix 5: Case Study

Appendix 5(a): Case Study

Several concerned organizations have contributed to this pack which is distributed by: the Asbestos Victims Support Groups Forum UK