Velcade® and myeloma

Myeloma Infoguide Series
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Introduction

This Infoguide has been written for myeloma patients. It may also be helpful for their families and friends. It provides information about Velcade, a relatively new drug for the treatment of myeloma.

Some of the more technical words appear in bold the first time they are used and are described in the Medical terms explained section on page 20.

This Infoguide aims to:

- Provide you with information about Velcade
- Answer some of the questions you may have about Velcade
- Help you to make informed decisions about the treatment options available to you

Myeloma UK provides a range of Infoguides and Infosheets on the treatment and management of myeloma and other topics relevant to patients and carers. You will find a list of the information available at the back of this Infoguide.

For more detailed information about myeloma and living with myeloma, see Myeloma – Your Essential Guide and Living with Myeloma – Your Essential Guide.

To order your free copies call the Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland. This information is also available to download at www.myeloma.org.uk

To talk to one of our Myeloma Information Specialists about any aspect of myeloma, call the Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland. The Myeloma Infoline is open from Monday to Friday, 9am to 5pm and is free to phone from anywhere in the UK and Ireland. From outside the UK, call + 44 (0)131 557 9988 (charged at normal rate). Information and support about myeloma is also available around the clock at www.myeloma.org.uk

Disclaimer

The information in this Infoguide is not meant to replace the advice of your medical team. They are the best people to ask if you have questions about your individual situation.
What is Velcade?

Velcade (also known as bortezomib) is the first in a new class of anti-cancer drugs called proteasome inhibitors.

Since its introduction, Velcade has had a significant positive impact on the treatment of myeloma. Its multiple mechanisms of action have proven to be highly effective in targeting myeloma cells causing a rapid reduction in paraprotein levels.

How does Velcade work?

Velcade works by temporarily blocking the actions of proteasomes. Proteasomes are involved in the removal, breakdown and recycling of damaged proteins or those that are no longer needed by the cell. See Figure 1.

As a consequence of temporarily blocking the actions of proteasomes, these proteins build up and become toxic, confusing the cell, and so cause it to die.

Dividing myeloma cells rely more heavily on proteasomes than normal healthy cells, which divide slowly. They are therefore much more sensitive to Velcade.

Although healthy cells are often affected by Velcade, they are able to survive and recover quickly from the dose of Velcade used to treat myeloma.
Through its action of blocking the functioning of the proteasome, Velcade is thought to work in the following additional ways:

- Directly killing myeloma cells
- Altering the production of chemical signals crucial for the growth and survival of myeloma cells
- Preventing myeloma cells from sticking to the bone marrow stroma
- Blocking the growth of new blood vessels (anti-angiogenesis) that supply myeloma cells with oxygen and nutrients
How is Velcade administered?

Velcade is normally given intravenously (into the vein). Increasingly it can also be given via a subcutaneous (into the skin) injection. You should speak to your doctor to find out which options are available at your hospital and which is most suitable for you.

**Intravenous injection**

Velcade is usually given as an intravenous injection. The injection itself lasts only three to five seconds.

To protect the veins and to reduce possible side-effects at the injection site, intravenous fluids (saline) will be given before and after Velcade is administered. This helps to flush the veins and keep you adequately hydrated to reduce the risk of a drop in blood pressure (see page 14).

Together with blood tests that are required beforehand, it may take a few hours to receive the Velcade treatment.

**Subcutaneous injection**

Velcade is increasingly given as a subcutaneous injection. This follows recent research evidence that this route of administration is as effective as intravenous injections, but crucially reduces the severity of a common and usually debilitating side-effect known as **peripheral neuropathy**.
As treatment for myeloma is often most effective when two or more drugs, with different but synergistic and complementary mechanisms of action, are given together, Velcade is usually given with the steroid dexamethasone. Other treatments, such as the chemotherapy drugs cyclophosphamide, melphalan or adriamycin, may also be given as part of the treatment combination.

Is Velcade given alone or in combination?

What is the dose, duration and frequency of treatment?

The exact dose, duration and frequency will depend on a number of factors and will vary between patients. These include:

- The clinical situation at hand and any individual patient factors
- Your height and weight
- Whether you are receiving treatment in a once-weekly or twice-weekly schedule
- At what stage of your myeloma you are receiving Velcade treatment
- What the Velcade-containing treatment combination you are receiving is

As with all the treatments, the dose can then be modified according to how well you are responding to the treatment and the extent to which its possible side-effects are causing problems.

In all cases, you should speak to your doctor/nurse about the exact dose, duration and frequency of your Velcade treatment.
How will I know if Velcade treatment has worked and what response should I expect?

The aim of anti-myeloma treatment combinations is to reduce the number of myeloma cells in the bone marrow and therefore reduce the paraprotein levels in the blood and/or free light chains in the urine. A response to treatment usually corresponds to an improvement in quality of life.

However, as with all treatments for myeloma, it is difficult to predict exactly how each patient will respond.

Response to treatment depends on a number of factors, including the individual nature of your myeloma, the number and type of any previous treatment and any side-effects you have with the treatment.

In general, your doctor will measure your response to treatment according to a defined set of criteria (see Appendix 1 on page 24). You may also get an idea of whether your treatment has worked by:

- An improvement in symptoms and complications
- An improvement in overall general health which, however, may not be clearly apparent until treatment is finished as side-effects may mask the benefits temporarily
- An improvement in quality of life

It is also possible to get an indication of how well you might respond to treatment from looking at clinical experience and data from clinical studies.

Some of these clinical studies provided the evidence for the approval of Velcade as a treatment for myeloma (see ‘The availability of Velcade on the NHS’ on page 15). With data from a key clinical study called VISTA, Velcade recently gained approval for use on the NHS for newly diagnosed patients and previously untreated patients under certain circumstances. Several years prior to this, Velcade was approved for use at relapse following evidence from pivotal studies at relapse.
Details of some of these studies are described below.

**Newly diagnosed myeloma**

Data from the pivotal clinical study called the VISTA trial suggested that over 70% of newly diagnosed patients, not considered suitable for *high-dose therapy* and *stem cell transplantation*, who were treated with a combination of Velcade, melphalan and *prednisolone* (VMP), achieved a *partial response* (PR) or *complete response* (CR), lasting for an average of 17 months.

The study also found that 43% of patients treated with VMP had a treatment-free period that was longer than two years.

**Relapsed myeloma**

Data from the pivotal international clinical study (the APEX trial) indicated that over 40% of relapsed myeloma patients had a partial or complete response to Velcade on its own. The *duration of response* lasted for approximately one year.

However, as stated previously, Velcade is most often given in combination with dexamethasone. This combination produces at least a PR in over 60% of relapsed patients. The improved effectiveness of combining these two drugs means that current standard practice is usually to prescribe both together.

Response to treatment can be further improved by adding other treatments. For example, data from one study showed that the addition of cyclophosphamide to Velcade and dexamethasone produced a CR or PR of 75% compared to 47% with Velcade and dexamethasone and 27% with Velcade alone. Therefore, some doctors may add cyclophosphamide to the standard combination of Velcade and dexamethasone.
What are the potential side-effects of Velcade and how are they treated and managed?

As with all drugs, Velcade has a number of potential side-effects. They vary considerably from patient to patient and may be mild or more serious. As side-effects can usually be treated or managed, it is very important to highlight them promptly to your doctor/nurse.

The only way your doctor/nurse will know what side-effects you have, is if you tell them. The earlier they are alerted to the development of side-effects the sooner they can help minimise the potential consequences of treatment-related side-effects.

Often the best way to reduce side-effects is to lower the dose and/or change the schedule of Velcade i.e. to once-weekly. There is evidence that a lower dose of Velcade is still effective but produces fewer side-effects. Unfortunately, if side-effects remain troublesome, it may be necessary to stop treatment altogether and consider other options.

The most common side-effects of Velcade include:

**Peripheral neuropathy**

Peripheral neuropathy is the term used to describe damage to the nerves in the hands, feet, arms or legs. This can cause numbness, tingling, increased sensitivity and pain. It is by far the most significant and problematic side-effect of Velcade, affecting up to 30% of patients.

Peripheral neuropathy can also be caused by other myeloma treatments, such as thalidomide and vincristine, as well as by the myeloma itself. Recent research suggests that the risk of treatment-induced peripheral neuropathy may be genetically influenced.

The best way to prevent peripheral neuropathy is to be vigilant and report any symptoms, such as numbness, tingling and any changes in sensation to your hands and feet, to your doctor/nurse as soon as possible. Many hospitals use a questionnaire to record side-effects which can be very helpful as an objective record of symptoms.
If the peripheral neuropathy becomes problematic, the dose and frequency of administration of Velcade can be reduced to make the treatment more tolerable and reduce the risk of permanent damage. In the majority of cases symptoms will improve or disappear after the dose and/or frequency of administration of Velcade is reduced. Failure to do this can sometimes prevent your doctor from using other treatments in the future that have the same side-effect profile.

In some cases, Velcade may need to be temporarily stopped, or, if peripheral neuropathy is severe, discontinued and other options discussed.

Pain and discomfort due to Velcade-induced peripheral neuropathy can be alleviated by gentle massage, taking warm baths, using heat/cold packs and paying attention to posture. Nerve-related pain often requires specific pain-killing drugs, such as pregabalin and gabapentin.

Other interventions that have been reported to help symptoms of peripheral neuropathy include nutritional supplements such as vitamin B, folic acid, various amino acid supplements and massage with cocoa butter. However, these are not established treatments and the evidence relating to the benefits of these treatments is limited. You should discuss these options with your doctor first before you use them.

For more information see the Peripheral neuropathy Infosheet from Myeloma UK. To order your free copy, call the Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland. This information is also available to download at www.myeloma.org.uk

Low blood counts

Velcade may cause a decrease in the number of red blood cells, white blood cells and platelets in your blood. The most likely type of blood cell to be affected by Velcade is platelets. Although a drop in platelet counts (thrombocytopenia) has the potential to increase the risk of bleeding, it usually doesn’t. If, however, your blood platelet count does get too low you may be given a platelet transfusion.
A low red blood cell count may cause anaemia and fatigue. If you become anaemic you may need to have a blood transfusion or receive other drugs, e.g. erythropoietin, to help boost your red cell count.

A low white blood cell count may make you more susceptible to infection. You may need to take extra precautions, such as avoiding crowded places and asking family and friends if they have an infection themselves, such as a cold or cough, not to visit you. If your white cell count is very low you may be given drugs, e.g. granulocyte-colony stimulating factor, to increase your white blood cell count.

Your blood counts will be measured each time you go for your Velcade treatment to check that they are within the normal range. In some cases, your next treatment with Velcade may be delayed until your blood counts have improved. This may take a few weeks but should not affect the activity of the myeloma and it does not mean that your myeloma will suddenly progress without immediate treatment.

Gastrointestinal disturbances

Velcade can cause diarrhoea, constipation, nausea and vomiting. Whilst usually mild and easily manageable, these side-effects can become problematic in some cases. It is important to ensure a good fluid intake and maintain a balanced diet. Your doctor may prescribe specific medication, which can help prevent or control the symptoms so again it is very important to alert medical staff to the appearance of these side-effects as soon as possible.

Fatigue

One other potential consequence of Velcade is for you to feel fatigued. In some cases there may be a number of medical and non-medical strategies to deal with fatigue. Fatigue caused as a result of Velcade usually resolves shortly after the treatment has finished.

For more information see the Fatigue Infoguide from Myeloma UK. To order your free copy, call the Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland. This information is also available to download at [www.myeloma.org.uk](http://www.myeloma.org.uk)
Low blood pressure

Velcade can cause a drop in blood pressure which can make you feel dizzy, lightheaded or like you are about to faint. If you have a history of hypotension (low blood pressure), or are on treatment to help lower your blood pressure, you may need to have your treatment lowered or stopped whilst you are on Velcade. Keeping well hydrated can help to prevent hypotension, especially during the time Velcade is administered.

Skin rashes

Some myeloma patients on Velcade treatment can develop a skin rash, which may be itchy and need treatment with antihistamines and/or steroid creams. If this is particularly troublesome, Velcade may need to be stopped temporarily and restarted at a lower dose.

Other, less common potential side-effects

As is usually the case with all treatments there are a number of other much less common side-effects that can occur, some of which are potentially serious. You therefore need to be alert to the development of any new and unexpected symptoms and make sure you alert your doctor/nurse as quickly as possible.

Interaction of Velcade with other medications and alcohol

You should tell your doctor if you are taking any other medications that they have not previously prescribed or do not already know about, including herbal and homeopathic remedies. Alcohol is generally not recommended. Its intake should be strictly limited while taking Velcade because it can exacerbate side-effects such as dizziness and fatigue.
The availability of Velcade on the NHS

When there is enough evidence to show that a new treatment is both safe and effective, it can be licensed for use in patients by the regulatory authorities. However, a treatment can only become available on the National Health Service (NHS) when it has been approved by the National Institute for Health and Clinical Excellence (NICE) or other devolved Health Technology Assessment bodies such as the Scottish Medicines Consortium (SMC) or the All Wales Medicines Strategy Group (AWMSG).

Velcade received its licence for use in myeloma in 2003 but, like most new treatments, was approved for use at relapse before being approved for use as front-line treatment i.e. newly diagnosed or previously untreated myeloma.

Front-line treatment

Velcade received its approval for front-line use in myeloma in July 2011. However, it is limited to patients who are not candidates for high-dose therapy and stem cell transplantation who are unable to tolerate or have contraindications to thalidomide.

Treatment at relapse

Velcade was approved for use on the NHS at first relapse in 2007. In some areas and circumstances it also became available at second and/or subsequent relapse.

In the relapsed setting, Velcade treatment is conditional in part on a scheme called the Velcade Response Scheme (VRS).

This is a ‘money-back guarantee’ scheme, which means that the manufacturer of Velcade will reimburse the NHS if patients do not respond to Velcade after four cycles of treatment. The scheme was developed in talks between the National Institute for Health and Clinical Excellence (NICE), the Department of Health and the manufacturer to improve the cost effectiveness of Velcade. This scheme is now also in place in Scotland.

If a patient achieves at least a 50% or greater reduction in their paraprotein (partial or complete response) after four cycles of Velcade, they are considered to have responded to Velcade.
Under the scheme, patients who achieve at least a PR will continue on Velcade. Those who do not will stop Velcade treatment and their doctor will discuss other treatment options with them.

In cases where patients do not have measurable paraprotein in their blood e.g. if they have light chain myeloma, response to Velcade treatment is defined by measuring urine free light chains. Under these circumstances, partial response is defined as a reduction of at least 90% urine free light chains within four cycles of Velcade treatment.

The VRS is not applicable to front-line treatment.

Other

In some circumstances, Velcade may not be approved for use. Where this is the case, one of the following mechanisms may be used to help gain access:

- **Individual Funding Request** (IFR) – the IFR system enables a doctor to make a request to the local Primary Care Trust or Local Health Board on behalf of a patient to fund a drug which is not normally available. When applying, the doctor must present a case that there is an exceptional reason why the patient needs the drug. A significant number of requests are successfully met this way.

- **Copayment system** – this system allows a patient to pay privately for a licensed drug (with the doctor’s support) while remaining an NHS patient for all other aspects of their treatment and care.

- **Cancer Drugs Fund** – this fund is intended to make sure that when a doctor wants to prescribe a specific drug for their patient, the Local Health Board will have the extra money to pay for it, regardless of whether the drug has been approved or not by NICE.

For specific information regarding access to new drugs, wherever you are in the UK, contact Myeloma UK.
The use of Velcade in clinical studies

Although Velcade is an established anti-myeloma treatment, it is continuing to be researched across all stages of myeloma to find better ways it can be used. It is being studied in combination with other currently available treatments and with novel treatments both in newly diagnosed and in relapsed and/or refractory patients.

Table 1 shows some of the current clinical studies being conducted across the world.

<table>
<thead>
<tr>
<th>Stage of myeloma</th>
<th>Description</th>
</tr>
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</table>
| Newly diagnosed        | • Velcade in combination with Revlimid® and dexamethasone  
                        | • Velcade in combination with Revlimid, dexamethasone and Doxil®  
                        | • Velcade in combination with cyclophosphamide, dexamethasone and Doxil  
                        | • Velcade in combination with the novel drug vorinostat, Revlimid and dexamethasone |
| Relapsed/refractory    | • *Velcade in combination with adriamycin and dexamethasone followed by a second stem cell transplant  
                        | • *Velcade in combination with vorinostat  
                        | • *Velcade in combination with the novel drug panobinostat and dexamethasone  
                        | • *Velcade in combination with the novel drug KW-2478 |
| Smouldering myeloma    | • Velcade (low-dose) alone                                                                                                                                 |

* Being conducted in the UK

If you are receiving, or about to receive, Velcade as part of a clinical study then you should be given specific information about the clinical study and any other drugs involved in the study alongside Velcade.

If you are interested in taking part in a clinical study, you should speak to your doctor in the first instance.

For more information on the use of Velcade in clinical studies call the Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland.
The future

Velcade represents a major recent advance in the treatment of myeloma and the outcome for myeloma patients has improved dramatically with its use not only in increasing response rates but also overall survival.

However, as Velcade is a relatively new treatment, there is still much to learn about how best to use it in myeloma.

Ongoing clinical studies are looking at Velcade in combination with currently available and/or emerging novel treatments at different stages of myeloma. Results to date are promising and indicate that Velcade can safely and effectively combine with several current and novel treatments in a variety of sequences and schedules to improve response rates.

Despite its effectiveness for many patients, there are still some who do not respond well to Velcade. Much emphasis is being placed on finding out why this may be, with attention being focused on a better understanding of the genetics of myeloma. It is hoped that this information will identify features of myeloma that can be used to predict a patient’s response to treatment. In future this will lead to more personalised treatment options for myeloma patients.

The success of Velcade has also led to second-generation proteasome inhibitors such as carfilzomib being developed. Carfilzomib monotherapy at second and subsequent relapse has shown encouraging durable responses in patients with relapsed myeloma, particularly in those patients who have become resistant to Velcade. It is also being tested in a combination with other current treatments and at different stages of myeloma. Importantly, carfilzomib appears to cause a lower incidence of peripheral neuropathy than Velcade. In addition, some of the new proteasome inhibitors are given orally.
Questions for your doctor/medical team

It can be helpful to write your questions down and give a copy to your doctor at the start of your consultation.

You might want to carry a piece of paper with you so you can make a note of questions as they occur to you.

Some questions you may need answering include:

- Would Velcade help me?
- Is Velcade being given to me as part of a clinical study?
- What are the aims of treatment with Velcade?
- Are there any alternative treatments?
- Is Velcade appropriate for me at this stage of my myeloma?
- How experienced are you and your team in using Velcade?
- How long might I be on Velcade?
- What side-effects should I expect?
- Will I be given anything to prevent side-effects?
- What should I do if I have any side-effects?
- Which side-effects should I report urgently and to whom?
- What options are available if Velcade does not help or stops working?
Medical terms explained

Adriamycin: A type of chemotherapy called a cytotoxic antibiotic given intravenously. Also called doxorubicin.

Anaemia: A decrease in the normal number of red blood cells, or the haemoglobin that they contain, causing shortness of breath, weakness and tiredness.

Anti-angiogenesis: Inhibition of the growth of new blood vessels.

Antihistamine: A drug used to treat an allergy.

Bone marrow: The soft, spongy tissue in the centre of bones that produces white blood cells, red blood cells and platelets.

Cancer Drugs Fund: It is a temporary measure designed by the Government to improve access to cancer drugs that are not available for routine use on the NHS.

Chemotherapy: Treatment with potent/cytotoxic drugs intended to kill cancer cells.

Clinical study (trial): A research study of a new treatment that involves patients following favourable results in laboratory experiments. Each study is designed to find better ways to prevent, detect, diagnose or treat cancer and to answer scientific questions.

Complete response (CR): Less than or equal to 5% plasma cells in bone marrow, no detectable paraprotein as defined by the International Myeloma Working Group (IMWG) uniform response criteria 2009.

Copayments scheme: A private payment for a drug or procedure by an NHS patient. It is usually used to purchase a drug or procedure that is not approved for use on the NHS.

Cyclophosphamide: A type of chemotherapy, known as an alkylating agent, used in the treatment of myeloma.
Dexamethasone: A synthetic steroid given alone or with other drugs in the treatment of myeloma.

Duration of response: The length of remission or plateau before further treatment is needed.

Free light chain: The smaller, lighter of two components which normally attach together to form the full paraprotein structure. Unattached light chains in the blood and urine are referred to as free light chains. In one type of myeloma, only free light chains are produced.

Gabapentin: A drug used to control nerve pain.

Granulocyte-colony stimulating factor: A synthetic type of a naturally occurring growth factor protein which stimulates a type of protein known as a growth factor which stimulates the bone marrow to make more blood cells.

High-dose therapy: High-dose chemotherapy which is given intravenously, usually via a central line, prior to giving back previously collected healthy stem cells as part of the transplantation process.

Individual funding request: The system in place which allows doctors to apply for drugs which are not normally available on the NHS.

Intravenous: A way of injecting drugs into the vein.

Melphalan: A type of chemotherapy known as an alkylating agent, used in the treatment of myeloma.

Paraprotein: An abnormal immunoglobulin (antibody) produced by myeloma cells and measured in the blood and urine. Measurements of paraprotein are used to help diagnose and monitor myeloma.

Partial response: Greater than or equal to 50% reduction of paraprotein in blood and greater than or equal to 90% 24-hour urinary paraprotein.
Peripheral neuropathy: Damage to the nerves, particularly in the hands and feet, causing pain, tingling, numbness and altered sensation.

Platelets: Small blood cells which are involved in blood clotting.

Prednisolone: A synthetic steroid given alone or with other drugs in the treatment of myeloma.

Pregabalin: A drug used to control nerve pain.

Proteasome: Proteasomes are involved in the removal, breakdown and recycling of damaged proteins or those that are no longer needed by the cell.

Proteasome inhibitor: A drug which works by blocking the function of the proteasome, leading to slowed cell growth or cell death.

Quality of life: A term which refers to a person’s level of comfort, enjoyment and ability to pursue daily activities. It is a measure of an overall sense of wellbeing.

Red blood cells: The blood cell which contains haemoglobin and carries oxygen from the lungs to all parts of the body.

Relapse: The point where myeloma returns or becomes more active after a period of remission or stable disease.

Response to treatment: The extent to which the activity of the myeloma has been reduced by a specific treatment. This is usually measured in terms of the reduction of paraprotein (or light chain) levels in the blood (or urine) along with the general improvement in overall health.

Side-effects: Problems that occur when treatment affects healthy cells and other tissues and organs in the body. Each treatment has its specific side-effects but the most common side-effects of standard cancer treatments include fatigue, nausea, vomiting, decreased blood cell counts, hair loss and mouth sores.
Stem cell transplantation: The infusion of healthy stem cells into the body. In myeloma, stem cell transplants are performed to allow the bone marrow to recover following high-dose chemotherapy. Stem cells are taken from the blood before the chemotherapy and are given back afterwards to renew the patient's blood-forming capacity. Stem cell transplantation is not a treatment but a method of support to make high-dose chemotherapy treatment possible.

Stroma: All tissue and cells in the bone marrow that are not directly involved in blood cell production.

Subcutaneous: Under the skin.

Thrombocytopenia: A lower than normal number of platelets in the blood. Normal levels range from 150,000 to 400,000 platelets per millilitre (ml) of blood. If the levels fall below 50,000 per ml of blood, bleeding problems may occur.

Vincristine: A type of chemotherapy that is used in the treatment of myeloma.

White blood cells: Blood cells involved in the body's immune system, which help to fight infection.
### Appendix 1

Criteria used to measure the response to treatment

<table>
<thead>
<tr>
<th>Treatment outcome</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stringent Complete Response (sCR)</td>
<td>Below normal free light chain ratio and absence of myeloma cells in bone marrow</td>
</tr>
<tr>
<td>Complete Response (CR)</td>
<td>5% or less plasma cells in the bone marrow; no detectable paraprotein</td>
</tr>
<tr>
<td>Very Good Partial Response (VGPR)</td>
<td>90% or greater reduction in blood and urine paraprotein</td>
</tr>
<tr>
<td>Partial Response (PR)</td>
<td>Greater than 50% reduction in blood paraprotein and a 90% reduction in 24h urinary paraprotein</td>
</tr>
<tr>
<td>Stable Disease (SD)</td>
<td>Not meeting criteria for CR, VGPR, PR or progressive disease</td>
</tr>
<tr>
<td>Progressive Disease</td>
<td>Increase of more than 25% in blood or urine paraprotein or the development of new myeloma-related symptoms</td>
</tr>
</tbody>
</table>
Further information and useful organisations

United Kingdom

Benefit Enquiry Line
0800 88 22 00 (Monday – Friday, 8.30am – 6.30pm; Saturday 9am – 1pm)
The Benefit Enquiry Line is a confidential advice and information service for people with disabilities, and their carers and representatives. The enquiry line provides information about social security benefits and how to claim them, and can provide assistance, over the phone, with filling out benefit application forms.

Blue Badge Scheme www.dft.gov.uk/transportforyou/access/bluebadge
0207 944 2914 (Blue Badge Helpline; Monday – Friday, 9am – 5pm)
The Blue Badge Scheme provides a national arrangement of on-street parking concessions enabling people with severe walking difficulties who travel, either as drivers or passengers, to park close to their destinations. To apply for a badge, contact the Social Services Department (or in Scotland the Social Work Department) of your local authority or council.

British Association for Counselling and Psychotherapy (BACP) www.bacp.co.uk
01455 883300 (General enquiries; Monday – Friday, 8.45am – 5pm)
01455 883316 (Client Information Helpline; Monday – Friday, 8.45am – 5pm)
BACP provides advice on a range of services to help meet the needs of anyone seeking information about counselling and psychotherapy. To find a local counsellor call the Client Information Helpline, or use the search facility on their website.

British Red Cross www.redcross.org.uk
0844 412 2804 (General enquiries; Monday – Friday, 9am – 5pm)
Volunteers assist with a range of local services – including care in the home, transport and medical loans – to help those with health issues lead a full and independent life. The Medical Equipment Service has a wide range of products and equipment available for short-term loan. The Home from Hospital Service provides short-term practical assistance and support to help people settle back into their own homes. A Transport and Escort Service offers help to people who cannot get about easily or use ordinary transport.
Cancer Black Care  www.cancerblackcare.org
020 8961 4151 (Monday – Friday, 9am – 5pm)
Cancer Black Care provides a unique service of information, advice and support for
the black and minority ethnic community.

The Cancer Counselling Trust  www.cancercounselling.org.uk
020 7843 2292  (Monday – Friday, 9am – 5pm)
The Cancer Counselling Trust offers a free telephone counselling across the UK. They
support cancer patients, their families, friends and care givers who seek counselling
to help them through the difficult issues precipitated by a cancer diagnosis. They
provide free, specialist counselling for anyone impacted by cancer, across the UK.

Cancer Research UK  www.cancerhelp.org.uk
0808 800 4040 (Nurse information line; Monday – Friday, 9am – 5pm)
CancerHelp UK is the patient information website of Cancer Research UK. They
provide a free information service about cancer and cancer care for patients and their
families.

Carer's Allowance Unit
01253 85 61 23 (Switchboard, ask for the Carer's Allowance Unit;
Monday – Thursday, 9am – 5pm; Friday 9am – 4.30pm)
General information about the carer's allowance, and assistance with filling in the
application form.

Carers UK  www.carersuk.org
0808 808 7777 (Wednesday and Thursday, 10am – 12noon, 2pm – 4pm)
Carers UK provides advice, information and support for carers. It produces a
directory of national and local carer organisations and can show you where to get
help in your area.
Citizens Advice Bureau (CAB)  
www.nacab.org.uk  
020 7833 2181 (Monday – Friday, 8am – 6pm)  
Citizens Advice Bureau offers advice about debt and consumer issues, benefits, housing, legal matters and employment. It provides assistance with claiming welfare benefits, including practical help with filling out benefit application forms. Contact the number listed above, use its website, or check your local telephone directory for details of your nearest branch.

Crossroads  
www.crossroads.org.uk  
0845 450 0350 (Monday – Friday, 9am – 5pm)  
Crossroads employs trained care support workers whose role is to relieve the family carer by giving them a break from their caring responsibilities, providing the carer ‘time to be themselves’.

Cruse Bereavement Care  
www.cruse.org.uk  
0844 477 9400 (Monday – Friday, 9.30am – 5pm)  
Cruse Bereavement Care exists to promote the well-being of bereaved people and to enable anyone bereaved to understand their grief and cope with their loss. The organisation provides face-to-face and telephone support, counselling and information.

Depression Alliance  
www.depressionalliance.org  
0845 123 2320  
(Information pack request line only; Monday – Thursday, Friday, 10am – 2pm)  
Provides information, support and understanding for those affected by depression and coordinates a network of self-help groups throughout the UK. Depression Alliance also produces a wide range of publications covering various aspects of depression.

DIAL UK  
www.dialuk.info  
01302 310 123 (Monday – Friday, 10am – 4pm)  
DIAL UK is a national organisation for a network of approximately 120 local disability information and advice services run by and for disabled people. DIAL provides information and advice on all aspects of living with a disability, including welfare benefits, transport, mobility and equipment.
Directgov  www.direct.gov.uk
A government website which provides information about a wide range of public services including benefits such as Attendance Allowance, Disability Living Allowance and Carer’s Allowance.

Disability Benefits Unit
0845 712 3456 (Monday – Friday, 7.30am – 6.30pm)
Provides advice and information about the Attendance Allowance and the Disability Living Allowance. Call to request a claim pack.

Financial Services Authority (FSA)  www.moneymadeclear.fsa.gov.uk
0845 606 1234 (FSA Consumer Helpline; Monday – Friday, 8am – 6pm)
The Financial Services Authority is the watchdog set up by government to regulate financial services. Money Made Clear is an online service from the FSA to provide clear, impartial information about financial products and services, helping you to make an informed decision.

Help the Hospices  www.hospiceinformation.info
Hospice Information Service
020 7520 8222 (Monday – Friday, 9am – 5pm)
Help the Hospices provides information to health professionals and the general public about hospice and palliative care services in the UK. Its online and telephone service can help you find a local hospice.

Help with Health Costs  www.nhs.uk/Healthcosts
0845 850 1166 (Monday – Friday, 8am – 6pm; Saturday, 9am – 3pm)
Help with Health Costs gives information about prescription charges and getting help with health costs. It also issues exemption from health costs certificates, and prescription pre-payment certificates.

Independent Financial Advice Promotion (IFAP)  www.ifap.org.uk
IFAP is the industry body responsible for promoting independent financial advice in the UK. It provides a UK-wide list of authorised financial advisers on its website. IFAP also produces a wide range of publications covering various aspects of financial management including mortgages, savings, investments and pensions.
Institute for Complementary and Natural Medicine (ICNM)  www.i-c-m.org.uk
0207 922 7980 (Monday – Friday, 10am – 4pm)
The Institute for Complementary and Natural Medicine (ICNM) provides the public
with information about all aspects of complementary medicine. It also administers
the British Register of Complementary Practitioners, providing details of local
registered practitioners of various complementary therapies.

Job Centre Plus  www.jobcentreplus.gov.uk
0800 055 6688 (Monday – Friday, 8am – 6pm)
Information and claims service for income support, incapacity benefit, job seekers
allowance and employment and support allowance. (Incapacity benefit was replaced
by Employment and Support Allowance for new claims from October 27 2008.)

Leukaemia CARE  www.leukaemia-care.org.uk
0800 169 66 80 (24 hours a day, 7 days a week)
Leukaemia CARE exists to provide care and support to all those whose lives have
been affected by leukaemia, lymphoma, myeloma and the allied blood disorders.
Leukaemia CARE also offers discretionary financial assistance and caravan holidays in
the UK.

Leukaemia & Lymphoma Research  www.llresearch.org.uk
020 7405 0101 (Monday – Friday, 9am – 5pm)
Leukaemia & Lymphoma Research funds research into leukaemia and related blood
disorders including lymphoma and myeloma. It also provides free patient information
booklets with accessible and accurate information on blood cancers and the related
disorders.

0800 500 800 (Monday – Friday, 10am – 5pm)
Macmillan Cancer Support offers information about how to access benefits and
other kinds of financial support.
Macmillan Cancer Support  
0808 808 0000 Macmillan Support Line; Monday – Friday, 9am – 9pm
0808 808 0121. If you are deaf or hard of hearing you can use the textphone service.

Marie Curie Cancer Care  
0800 634 4520 (Monday – Sunday, 9am – 10.30pm)
Marie Curie provides specialist palliative nurses and has ten Marie Curie Centres providing free respite and hospice care throughout the UK.

MedicAlert®  
0800 581 420 (Monday – Friday, 9am – 5pm)
MedicAlert is a non-profit charity that provides a life-saving identification system for individuals with hidden medical conditions.

Medical Research Council (MRC)  
020 7636 5422 (Head office switchboard; Monday – Friday, 9am – 5pm)
The MRC promotes research into all areas of medical and related science.

National Amyloidosis Centre (NAC)  
020 7433 2725 (General enquiries; Monday – Friday, 9am – 5pm)
Based at the Royal Free and University College Medical School, the NAC is the only centre in the UK specialising in amyloidosis. The centre has state of the art clinical and research facilities and a team of highly qualified clinical, research and support staff.

National Cancer Research Institute (NCRI)  
020 7061 8460 (Monday – Friday, 9am – 5pm)
The National Cancer Research Institute is a partnership of health departments, the Medical Research Council and major cancer charities which aims to develop common plans for cancer research.

National Debtline  
0808 808 4000 (Monday – Friday, 9am – 9pm; Saturday 9.30am – 1pm)
Offers free, confidential and independent advice on how to deal with debt problems.
National Institute for Health and Clinical Excellence www.nice.org.uk
0845 003 7780 (Monday – Friday, 9am – 5pm)
NICE is an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health. NICE produces guidance on health technologies (the use of new and existing medicines, treatments and procedures) and clinical practice (guidance on the appropriate treatment and care of people with specific diseases) within the NHS.

National Kidney Federation www.kidney.org.uk
0845 6010 209 (Monday – Friday, 9am – 5pm)
The National Kidney Federation provides information about kidney disease and dialysis, and promotes best practice in renal medicine.

0845 46 47 (NHS Direct; England, Northern Ireland and Wales)
0845 24 24 24 (NHS 24; Scotland)
Staffed by trained medical professionals, these organisations provide 24-hour access to information about all aspects of health and healthcare.

NHS National Library for Health www.library.nhs.uk
The NHS National Library for Health is aimed at NHS staff, patients and the general public and provides information on all aspects of health, illness and treatment.

OvercomeDepression www.overcomedepression.co.uk
OvercomeDepression aims to offer a unique reference point for information and practical advice on depression.

Pain Association Scotland www.chronicpaininfo.org
0800 783 6059 (Monday – Friday, 9.30am – 4pm)
Pain Association Scotland offers support to people with chronic pain and organises pain management support groups across Scotland.

Pain Concern www.painconcern.org.uk
01620 822 572 (Monday – Friday, 9am – 5pm; Friday, 6.30pm – 7.30pm)
Pain Concern provides a range of information about self-help and managing pain. Its helpline offers information, support and a listening ear.
Patient Advice and Liaison Services (PALS)  www.pals.nhs.uk
This service is available in England to provide patients and their families with
information regarding health related enquiries, NHS services and other support
available. It can provide information about the NHS complaints procedure and how
to get independent help if you decide you may want to make a complaint. You will
be able to find your local service through your hospital.

Penny Brohn Cancer Care  www.pennybrohncancercare.org
(formerly Bristol Cancer Help Centre)
0845 123 2310 (Monday – Friday, 9.30am – 5pm)
Based in Bristol, Penny Brohn Cancer Care offers specialist support including
complementary therapies, nutritional advice and counselling for people affected by
cancer. Their helpline provides emotional support and information about
complementary therapists and services in your area.

The Pensions Advisory Service  www.pensionsadvisoryservice.org.uk
0845 601 2923 (Monday – Friday, 9am – 5pm)
The Pensions Advisory Service is an independent non-profit organisation that
provides free information, advice and guidance on a spectrum of pensions covering
state, company, personal and stakeholder schemes.

The Pension Service  www.thepensionservice.gov.uk
0845 6060 265 (Pension helpline; Monday – Friday, 8am – 8pm)
0800 99 1234 (Pension credit information; Monday – Friday, 8am – 8pm)
08459 15 15 15 (Winter fuel payments helpline; Monday – Friday, 8am – 5pm)
Part of the Department for Work and Pensions, the pension service provides
information about pensions and benefits, for current and future pensioners.

Princess Royal Trust for Carers  www.carers.org
0844 800 4361 (Monday – Friday, 9am – 5pm)
The Princess Royal Trust for Carers is the largest provider of comprehensive carers
support services in the UK. Through its unique network of 144 independently
managed Carers’ Centres, 85 young carers services and interactive websites, the
Trust currently provides quality information, advice and support services to almost
354,000 carers.
Relate www.relate.org.uk
0300 100 1234
(Monday – Thursday, 8am – 10pm; Friday, 8am – 6pm; Saturday, 8am – 4pm)
Relate offers a confidential counselling service for couples or individuals experiencing difficulties in their relationship. Relate provides support face-to-face, by phone and through its website.

Royal Association for Disability and Rehabilitation (RADAR) www.radar.org.uk
020 7250 3222 (Monday – Friday, 9am – 5.30pm)
RADAR is a national organisation for disabled people. It publishes information on all aspects of living with disability, including transport and mobility. RADAR runs the National Key Scheme, which offers disabled people access to 7,000 locked public toilets around the country.

Samaritans www.samaritans.org
08457 90 90 90 (24 hours a day, 7 days a week)
Samaritans provides confidential non-judgemental emotional support, 24 hours a day for people who are experiencing feelings of distress or despair. It offers services by telephone, email, letter and face to face.

SSAFA (Soldiers, Sailors, Airmen and Families Association) www.ssafa.org.uk
0845 1300 975
A national charity committed to supporting those who serve or have served (even for just one day) in our Armed Forces. It offers a Confidential Support Line, financial assistance, help in organising and funding home adaptations or special equipment and practical/emotional support for those who are lonely, bereaved or ill.

Tenovus Cancer Information Centre www.tenovus.org.uk
0808 808 1010 (Monday – Friday, 9am – 5pm)
Tenovus is a charity committed to the control of cancer through research, education, counselling and patient care. Its helpline offers information and support to those affected by cancer.
The UK Myeloma Forum is an organisation of people professionally engaged in the field of myeloma who are working to improve the outlook for patients with myeloma and related disorders. On behalf of the British Committee for Standards in Haematology, UKMF has produced guidelines on the diagnosis, treatment and management of myeloma.

Ulster Cancer Foundation (Northern Ireland)   www.ulstercancer.org
0800 783 3339 (Monday – Friday, 9am – 5pm)
The Ulster Cancer Foundation offers information, support and counselling to people affected by cancer in Northern Ireland. Its helpline is staffed by specially trained nurses with experience in cancer care. It also runs a Myeloma Support Group.

Ireland

ACCORD   www.accord.ie
01 505 3112
Caring for marriage and relationships. It is the largest marriage-care agency in Ireland.

Association of Registered Complementary Health Therapists of Ireland   www.irishtherapists.ie
053 938 3734
It acts as an umbrella association in order to promote better awareness of complementary health medicine.

Care   www.carers.ie
01 679 3188
Carers provide practical information and guidance for people who are caring for someone who has been diagnosed with a life-threatening illness in Ireland.

Chronic Pain Ireland   www.chronicpainireland.org
01 804 7567 (Monday – Thursday, 9.30am – 5pm)
Chronic Pain Ireland provides information and support to those living with chronic pain, their families and friends.
Citizens Information  www.citizensinformation.ie
Citizens Information is an Irish eGovernment website provided by the Citizens Information Board. The site provides public service information for Ireland.

Ireland out of hours (carers)  
For Ireland out of hours contacts: 
www.hse.ie/eng/services/Find_a_Service/Primary/GP_Out_of_Hours

Irish Cancer Society  www.cancer.ie
1 800 200 700 (Monday – Thursday, 9am – 7pm, Friday, 9am – 5pm)  
From the UK dial 00 353 1 2310 500
The Irish Cancer Society provides advice, support and information to people in Ireland affected by cancer. It also publishes a range of patient information, including a booklet on myeloma.

The Irish Hospice Foundation  www.hospice-foundation.ie
01 679 3188 (Monday – Friday, 9am – 1pm, Monday – Thursday, 2pm – 5.30pm, Friday 2pm – 5pm)  
Works independently and in partnership with the statutory, voluntary and professional bodies with hospice and palliative care in Ireland.

MyMyeloma  www.mymyeloma.ie
087 233 7797  
Dedicated Irish myeloma website for patients, family members and those with an interest in myeloma.

Overseas

Myeloma Euronet  www.myeloma-euronet.org
00 49 30 2887 9755  
A non-profit network organisation of myeloma patient groups, is a European initiative dedicated to raising awareness of myeloma. It provides information about diagnosis, treatment and care, as well as support for families and loved ones.
The MMRF is a US-based private funder of worldwide myeloma-specific research. It provides information about myeloma treatments and international clinical studies.

For a complete list of useful organisations see *Myeloma – Your Essential Guide* from Myeloma UK. To order your free copy, call our Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland. This information is also available to download at www.myeloma.org.uk
With Myeloma UK you can...

- Call our Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland for information, practical advice, emotional support and a listening ear
- Get free Infopacks, Infoguides and Infosheets about myeloma
- Learn about myeloma from experts and meet others affected by myeloma by attending Patient and Family Myeloma Infodays
- Subscribe to our newsletter Myeloma Matters
- Visit our website www.myeloma.org.uk
- Join a Myeloma Support Group
Other information and support available from Myeloma UK

Essential Guides
Myeloma – Your Essential Guide
Living with myeloma – Your Essential Guide

Infoguides
Infoguide topics include:
- Balloon Kyphoplasty
- Myeloma Bone Disease and Bisphosphonates
- Caring for someone with myeloma
- Clinical Studies
- Fatigue
- High-Dose Therapy & Stem Cell Transplantation
- Myeloma XI
- Pain and myeloma
- Revlimid and myeloma
- Serum Free Light Chain Assay
- Thalidomide and myeloma

Leaflets
- Myeloma – An Introduction
- About Myeloma UK
- Myeloma UK – Publications list

Infosheets
Infosheet topics include: Biosimilars, Constipation, Copayments, Diet and Nutrition, Erythropoietin, Fatigue, Growth Factors, Managing Your Finances (Benefits and General), MGUS, Mouthcare, Osteonecrosis of the Jaw, Pain, Peripheral Neuropathy, Percutaneous Vertebroplasty, Plasmacytoma, Plasmapheresis, Prescription Charges, Radiotherapy, Setting up a Support Group, Smouldering Myeloma, Steroids, Strength activities for people with myeloma, Stretches for people with myeloma, Support Groups, Swine Flu, The kidney, Travel Insurance, Travelling.
Horizons Infosheet Series:

These provide information on a number of treatments and procedures that are in the final stages of research or development and which are showing a great deal of promise. Current Horizons Infosheets: Bendamustine, Carfilzomib and Pomalidomide.

Patient diary
This diary helps patients keep a track of hospital appointments and key test results in a practical, simple way. The diary (A5 in size) contains 11 sections which are neatly divided and tabbed for ease of reference as follows: Your myeloma diary, Appointments, Blood tests and results, Treatment records, Complementary therapies record, Symptoms and side-effects record, Questions to ask your doctor /nurse, Key myeloma terms, Further information and useful organisations, About Myeloma UK and Your notes.

PEER Network

PEER Members are patients, family members and carers who are willing to share and communicate with others affected by myeloma who contact Myeloma UK and are seeking information, support and reassurance from someone who has been in or is currently in a similar situation.

To order any of our free publications or for information about any of the support that we can offer, call our Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland. The Myeloma Infoline is open from Monday to Friday, 9am to 5pm, and is free to phone from anywhere in the UK and Ireland. From outside the UK, call +44 (0)131 557 9988 (charged at normal rate).

Myeloma UK also provides information on conditions associated with myeloma; this includes information about AL amyloidosis, plasmacytoma, MGUS (Monoclonal Gammopathy of Undetermined Significance) and Waldenström’s Macroglobulinaemia.
We need your help

We rely almost entirely on voluntary donations and fundraising activities to fund our broad range of services from providing information and support, to improving standards of treatment and care through research, education, campaigning and raising awareness.

That is why we need your help.

We depend on the support and generous donations from people like you to provide these important services, which are available free to myeloma patients, their families and carers.

A guide to how your donation will help others:

- £2 will ensure that another patient receives a booklet about myeloma
- £12 will fund an Information Pack for a newly diagnosed patient and their family
- £75 will pay for our quarterly newsletter, *Myeloma Matters*, to be sent to three people for a year
- £100 will enable us to provide a start-up grant to a new Myeloma Support Group
- £188 will pay to genotype one DNA sample
- £582 will fund a month’s worth of information to be mailed out to patients, their families and carers
- £1,019 will pay for a Myeloma Nurse Specialist for a working week
- £35,000 will pay for one research nurse for a year

All donations are greatly appreciated and allow us to continue our vital work.
How to donate

You can make your donation online at www.myeloma.org.uk, over the phone by calling +44 (0)131 557 3332, or by posting a cheque or CAF voucher made payable to Myeloma UK to our office – the address is on the back of this Infoguide.

Gift Aid it

Remember to let us know if you are a UK tax payer, so we can increase your gift by claiming the tax back from the Government. If you are a UK tax payer, Myeloma UK can claim Gift Aid on your donation. At present for every £1 that you donate we can claim 25p. This extra money comes from the Government, so it doesn’t cost you any extra.

There are other ways you can support Myeloma UK such as taking part in an organised event, or by fundraising for Myeloma UK in your local community.

When so much about myeloma is beyond the control of the people that it affects, fundraising can be a rewarding and fun way of doing something positive.

Contact the fundraising team on +44 (0)131 557 3332 for more information or visit www.myeloma.org.uk
Published by: Myeloma UK
Publication date: April 2007
Printed: October 2011
Updated: October 2011

Myeloma UK would like to thank Dr Judith Behrens, Consultant Haematologist, Prof Curly Morris, Consultant Haematologist MBE, Dr Faith Davies, Consultant Haematologist, Sue Blair RGN, Myeloma CNS and Tracy Howe RGN, Myeloma CNS for their invaluable help and advice in the compilation of this Infoguide.

Myeloma UK publications are extensively reviewed by patients and healthcare professionals prior to publication.
Call our Myeloma Infoline on 0800 980 3332 or 1800 937 773 from Ireland
www.myeloma.org.uk