Infopack for relapsed and/or refractory myeloma patients.
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Introduction

Who is this Infopack for?

This Infopack is for myeloma patients, particularly those whose myeloma has returned following or during treatment; in other words, relapsed and/or refractory patients. Family members and friends may also find it useful to read.

You may be reading because you have found out you have relapsed or are refractory to treatment, or you may be reading to prepare yourself for these possibilities. Either way, it focuses on what you need to know about relapsed and refractory myeloma.

What does the Infopack contain?

When myeloma returns it can be a particularly difficult time for patients and their families. When relapsed and/or refractory myeloma is diagnosed, it may come as less of a shock than the initial diagnosis but it can be just as challenging and can raise its own set of questions and concerns. These include:

- Why does myeloma relapse?
- How will I/my doctor know I have relapsed?
- Do I need to start treatment straight away at relapse?
- Will I have the same treatment I had following my diagnosis?
- Why does myeloma become refractory to treatment?
- Will new treatment make my existing side-effects worse?
- How well will the new treatment work?
- How many relapses will I have?

The Infopack is intended to answer these and other questions, and help you come to terms with a relapse or being refractory to treatment.
How should I use this Infopack?

You should read this Infopack at your own pace. You may find it easiest to read in bite-size chunks. It has been split into sections to help you navigate the information as and when you need or want to.

At the end of the Infopack there is information on how to access more in-depth information about myeloma from Myeloma UK.

There is also a glossary to explain the medical terms that appear in bold throughout.

How has the Infopack been developed?

The information in this Infopack has been gathered together from patients, their families and carers who have gone through what you are currently going through. Patients and healthcare professionals were also involved in reviewing the Infopack prior to publication.
Myeloma is a type of cancer arising from **plasma cells** that are normally found in the **bone marrow**. Plasma cells are a type of **white blood cell** which form part of the **immune system**.

Normal plasma cells produce different types of **antibodies** (also called immunoglobulins) to help fight infection. In myeloma, the plasma cells become **malignant** and release a large amount of a single type of antibody, known as **paraprotein**, which has no useful function. In some patients, the abnormal plasma cells produce only part of the paraprotein structure, called light chains.

Most of the complications and symptoms of myeloma are caused by a build-up of the abnormal plasma cells (often called myeloma cells) in the bone marrow and the presence of paraprotein or light chains in the blood or in the urine. Common problems include bone pain, bone fractures, tiredness due to **anaemia**, frequent or recurrent infections (such as chest infections, urinary tract infections and shingles), kidney damage and **hypercalcaemia**.

Myeloma is highly treatable in the majority of cases. Treatment for myeloma is aimed at disease control, relieving the complications.
and symptoms it causes, and extending and improving the quality of life.

While there are many effective treatments for myeloma, it is currently incurable. This means that even after successful treatment has provided a period of remission or plateau (also known as stable disease), the myeloma will return. This is called a relapse.

In some cases, the myeloma develops resistance to, or does not respond to, treatment. This is called refractory myeloma.

This Infopack covers both relapsed and refractory myeloma.
What is relapsed myeloma?

Myeloma is a relapsing-remitting cancer, which sets it apart from many other cancers.

‘Relapsing-remitting’ means there are periods when the myeloma is active and causing problems in the body and needs to be treated. Successful treatment aims to bring the myeloma back under control and a period of plateau or remission follows, where the myeloma does not cause symptoms and does not require treatment.

After reaching remission or plateau, many patients will remain well for some time without the need for further treatment. It may be months or years before the myeloma becomes active again. However, at some point after a period of treatment and plateau or remission, the myeloma will become active again and further treatment is required. This is called a relapse.

A relapse following a period of remission or plateau is, unfortunately, inevitable at some point. Patients are monitored regularly to ensure that a relapse is detected as early as possible. Relapses can happen several times during the course of the disease. See Figure 1 (overleaf) for a visual representation of the course of myeloma.
Sometimes, the myeloma develops resistance to particular treatment, or does not respond to it at all. This is called refractory myeloma (see Figure 2).
Some separate information on refractory myeloma is provided in Section Six; however, much of the information that applies to relapsed myeloma also applies to refractory myeloma, so the other sections in the Pack will also be relevant for refractory patients.

**Why does relapse occur?**

Relapse occurs in myeloma because current treatments are not able to kill all of the myeloma cells. This is as a result of the underlying biology of myeloma, and how it develops and progresses.

Myeloma begins when the genetic material of a plasma cell is damaged during its development. Some genetic abnormalities occur early on in the development of myeloma but abnormalities continue to occur within the myeloma cells as the myeloma progresses. Typically, relapsed patients have a greater number of abnormalities than newly diagnosed patients.

It is now also known that not all the myeloma cells in an individual patient are identical. Within any one patient there are different subpopulations (called clones) of myeloma cells.

At diagnosis, a myeloma patient has three to six major clones of myeloma cells, all of which have different genetic abnormalities and will respond differently to treatment. These different clones compete for space to grow within the bone marrow. When treatment is given it can kill most clones, but clones that are resistant to the treatment will survive, have more space to grow and come to dominate the bone marrow. In time, these new dominant clones lead to relapse (see Figure 3). This is a theory known as ‘clonal evolution’ and is responsible for disease progression in myeloma.

In addition to some of the clones being resistant to the treatment given, treatment may also not kill all of the myeloma cells within the clones that are susceptible to it. **Minimal residual disease** (MRD) is the name given to the tiny number of myeloma cells that remain in the bone marrow following successful treatment i.e. when the patient has no symptoms or measurable evidence of disease.

Over time, these residual cells multiply and grow to numbers large enough to cause relapse.
Figure 3. The clonal evolution of myeloma

normal cells → abnormal cell → abnormal clones → multiplication and further mutation → new subclone

TREATMENT

susceptible clones killed → resistant clones survive and eventually will start to multiply

new subclone
A relapse is diagnosed when, after a period of response to treatment, you begin to show signs and/or symptoms that the myeloma is becoming active again.

Throughout your myeloma, during and after treatment, your hospital doctor or nurse will carry out various tests (see Appendix) to monitor the activity of your myeloma as well as asking you about how you are feeling in general. This all helps to provide a picture of what is happening in your individual situation. The regular tests you will have, in addition to any new or increasing symptoms, can give a good indication as to whether your myeloma is becoming active again.
Generally speaking, myeloma that is relapsing is characterised by an increase in paraprotein or light chain levels and a reduction in the levels of the healthy blood cells such as red cells (causing anaemia), the white cells (causing an increased susceptibility to infection) or platelets (causing an increased risk of bruising or bleeding).

You might also get the first clues that you are relapsing through new (or an increase in) symptoms and complications related to your myeloma, such as an increase in bone pain or decreasing energy levels due to anaemia.

Many patients whose myeloma is relapsing describe having the same or similar symptoms to those they had when they were first diagnosed. However, you may develop new symptoms you have not had previously. For example you may develop kidney or bone problems even if you’ve previously not been affected by these complications. It is important that you report any new or increasing symptoms promptly to your doctor or nurse so that tests and investigations can be carried out to establish whether you have relapsed.

You might find yourself living with a heightened concern about any symptoms you have and whether they may be the first signs of relapse or of treatment not working. However, in most cases, your doctor will pick up signs of relapse before you notice an obvious deterioration in your general health.

**The importance of trends**

Paraprotein and/or light chain levels are very individual to each patient and can sometimes fluctuate up and down without causing too much concern. One result showing an increase in paraprotein levels does not necessarily indicate a relapse.

Your doctor will be looking at the trends over a period of time rather than be guided by one reading alone.

Usually an increasing trend of paraprotein levels over two or three consecutive readings and a deterioration in other blood readings (e.g. a lowering of haemoglobin levels or signs that the kidneys are becoming affected), alongside any new or increasing symptoms of pain, fatigue or recurrent infection would be more concerning than one change in any result in isolation.
How well you respond to initial treatment and therefore how long your myeloma is controlled in a period of remission or plateau is dictated by many factors and varies enormously from individual to individual. The disease process is complex and unpredictable and therefore the timing, nature and pace of relapse are very variable.

Some patients relapse a few weeks or months after completing their initial treatment; others will have many years of remission following initial treatment. The psychological impact of not knowing when a relapse will occur can take its toll, and anxiety before hospital appointments and test results is common. See Section Seven for information on coping with the emotional and psychological aspects of relapsed and/or refractory myeloma.

When relapse will occur is impossible to anticipate with any accuracy, but there are characteristics of myeloma which are known, to some degree, to influence how quickly a relapse might occur. Some of these are discussed overleaf.
Response to treatment
A deeper response to initial treatment is an important factor in generating a longer remission and delaying relapse. For example, patients who achieve a complete response following high-dose therapy and stem cell transplantation generally will have a longer period of remission or plateau before a relapse. This is not always the case, however.

Age, frailty and comorbidities
Over half of myeloma patients are over the age of 70, and many have other medical problems (comorbidities), mobility issues or need help from others with household tasks or personal care. Older, frailer patients can experience a higher rate of side-effects whilst on treatment and may also experience more symptoms and complications. This can then affect how they tolerate and respond to treatment and therefore how quickly they might relapse.

Genetic subtype
Myeloma is associated with multiple genetic abnormalities. Many of these abnormalities are within chromosomes in which genes are packaged (see Figure 4). Genetic abnormalities are detected from bone marrow samples using techniques such as fluorescence in situ hybridisation (FISH) and next-generation sequencing.
As explained on page 16, genetic abnormalities also continue to occur within the myeloma cells as the myeloma progresses. This means myeloma can evolve over time and become more resistant to the effects of treatment, causing relapses to occur more quickly.

Patients may not know if they have standard or high-risk abnormalities. Although this information can be of value in determining prognosis, current treatment is predominantly a one-size-fits-all approach meaning that high-risk patients are not generally treated differently to standard-risk patients. However, there is a great deal of ongoing research on how to overcome the high-risk features of myeloma. For example, it is known that bortezomib (Velcade®) is a more effective treatment than thalidomide for patients with the t(4;14) subtype of myeloma. The hope is that in the future, all patients will be tested for high-risk genetic features and grouped (stratified) so that they can be given the best treatment for them based on their genetic profile. Section Nine provides more information on this stratified treatment approach.

Myeloma can be grouped into genetic subtypes by the various chromosomal abnormalities that can occur.

Some common chromosomal abnormalities in myeloma include:
- t(4;14)
- t(14;16)
- 1q gain
- del(17p)
- t(11;14)
- Hyperdiploidy (a gain in chromosome number)

These chromosome abnormalities appear to influence how well a patient responds to treatment and the speed of relapse.

Some chromosomal abnormalities are associated with better treatment responses and prognosis, for example t(11;14) and hyperdiploidy. Patients with such abnormalities can be described as having ‘standard-risk’ myeloma.

Unfortunately, other abnormalities are associated with a more active or difficult to treat myeloma which may relapse more quickly after treatment. These are classified as ‘high-risk’ abnormalities and include t(4;14), t(14;16), 1q gain and del(17p).
Can I prevent a relapse?

Coping with the relapsing and refractory nature of myeloma can be very difficult. The knowledge that relapse is ‘looming’, but at an unspecified time, can generate fear and uncertainty about the future. Many patients ask if there is anything they can do to prevent or delay a relapse.

Unfortunately, there is nothing you can do to prevent the myeloma from returning. At the moment the causes of myeloma remain uncertain, and there is no direct correlation between myeloma and lifestyle or diet. Healthcare professionals will always advocate a healthy lifestyle, such as eating plenty of fruit and vegetables, taking gentle exercise and stopping smoking if you are a smoker, but none of these have been directly linked to the development or progression of myeloma.

However, the understanding about why relapse occurs is improving every day and researchers are working hard to develop strategies to overcome relapse (see Section Nine for more information).
There are many effective treatment options for relapsed myeloma.

The aim of treatment for relapsed myeloma is to control and slow down the progression of the myeloma, put you back into remission or plateau, relieve symptoms and give you the best quality of life, for as long as possible.

**Is treatment always necessary?**

Treatment for relapsed myeloma is always necessary to regain control of the myeloma, unless you decide you do not want any further treatment (see Section Eight). However, treatment is not always needed as soon as a relapse is diagnosed.

**When do I start treatment?**

There are no cast-iron criteria to determine when patients should start treatment at relapse, and the timing will vary from individual to individual. This is because treatment is always a balance between the need to bring the myeloma under control on the one hand, and not cause too many side-effects on the other.

As at diagnosis the decision to start treatment at relapse is often based on the emergence of new symptoms or the worsening of existing ones, coupled with a steady rise in paraprotein and/or
light chain levels. This is called a **clinical relapse**. Treatment is likely to start fairly quickly after a clinical relapse has been diagnosed.

When a patient’s paraprotein and/or light chain levels are starting to slowly rise but they have no symptoms or complications such as kidney problems or bone pain, this is called a **biochemical relapse** and the decision on when to start treatment becomes a trickier one.

The timing of treatment will depend on a number of factors including the speed at which the paraprotein and/or light chain levels rise – a patient with no symptoms is more likely to start treatment if their levels have started to rise rapidly over the course of a few months. Similarly, if a patient has had myeloma-related complications in the past, or has high-risk disease, a doctor is likely to start treatment earlier, before symptoms develop.

There is some evidence to suggest that treating earlier – that is, at signs of biochemical relapse rather than clinical relapse – is beneficial in terms of slowing down the progression of myeloma. However, until this is confirmed through more clinical trials, decisions about the timing of treatment remain at the doctor’s discretion in discussion with the patient.

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**Treatment options at relapse**

There are many treatment combinations available for relapsed myeloma. In addition, promising new drugs can be accessed in clinical trials and may soon be available on the NHS.

The exact treatment combination you will have at relapse will depend on many things, including:

- Whether it is your first or subsequent relapse
- The treatment you have had previously, and how you responded to it (**depth of response**)
- The length of remission or plateau you achieved from your previous treatment (**duration of response**)
- Any persistent side-effects following your previous treatment, such as **peripheral neuropathy** or low blood counts
- Whether you are known to be refractory to any treatment
- Your general health
- Your age and any existing myeloma-related complications, such as kidney problems
- Any comorbidities, such as diabetes or heart disease
- Your priorities and preferences
- What is licensed and approved for use on the NHS
- Evidence-based national guidelines
- Whether or not you take part in a clinical trial
Approved drugs/combinations for relapse
As is the case with all treatment for myeloma, treatment for relapsed myeloma is almost always with a combination of drugs. Treatment combinations are usually made up of two or three different types of drug and can include a chemotherapy drug, a steroid and another type of anti-myeloma drug, such as a proteasome inhibitor or an immunomodulatory drug. A course of treatment is usually given over periods of time known as cycles e.g. treatment over a few days or weeks, followed by a rest period without treatment before the next cycle is given.

Will I have the same treatment as I had first time round?
It is possible to repeat the initial treatment combination you had but generally only if you responded well to it (for example, if it gave you at least a 6 month period of remission). More commonly, the initial combination may be added to e.g. adding in a steroid or chemotherapy drug, or an entirely new treatment combination will be tried.

Treatment for first relapse
Commonly used treatment combinations at first relapse include:

A bortezomib-based combination
Bortezomib (Velcade) is a proteasome inhibitor drug. These drugs interfere with the normal functioning of part of the cell called the proteasome. Myeloma cells rely more heavily on proteasomes than normal, healthy cells. Proteasome inhibitors therefore cause myeloma cells to die while leaving healthy cells less affected.

At first relapse, bortezomib (given by injection) may be given with other drugs in various combinations:

- Bortezomib and the steroid dexamethasone
- Bortezomib, dexamethasone and the chemotherapy drug cyclophosphamide (known as VCD)
- Bortezomib, the immunomodulatory drug thalidomide and dexamethasone (known as VTD)
- Bortezomib, the chemotherapy drug doxorubicin (Adriamycin®) and dexamethasone (known as PAD)

A lenalidomide-based combination
Currently, in some parts of the UK, some groups of patients may receive a lenalidomide (Revlimid®)-based combination at first relapse.
Can I have a second stem cell transplant?

If you had successful treatment with high-dose therapy and a stem cell transplant (HDT-SCT) as part of your initial treatment, a second one at the time of relapse may be considered if you have enough stem cells stored that can be used. The option of a second HDT-SCT will depend on the timing of the relapse, your age, previous treatment and general health/fitness to be able to undergo the procedure again. Generally a second HDT-SCT will only be offered if you gained at least 18 – 24 months remission or plateau from your first HDT-SCT.

Results from a national myeloma trial called the Myeloma X trial showed that a second HDT-SCT is more effective than standard chemotherapy in myeloma patients who have relapsed following their first HDT-SCT. Other ongoing trials are also studying the effects of second HDT-SCT in relapsed myeloma patients.

The results from Myeloma X demonstrate the positive impact a second HDT-SCT can have in the treatment of relapsed myeloma. However, HDT-SCT is an intensive treatment option and can put a significant physical and emotional strain on patients and their families. Anecdotally, many patients say that a second HDT-SCT is an easier procedure to go through than the first as

For more information on bortezomib, lenalidomide or clinical trials, contact Myeloma UK

See our High-dose therapy and autologous stem cell transplantation Infoguide for more information

Infoline: 0800 980 3332
they know what to expect, whereas others say this makes it a more daunting prospect.

Your doctor will talk through the potential side-effects and risks of a second HDT-SCT with you, including the potential impact on your quality of life. It is important that the side-effects do not outweigh the benefits of treatment and that they are acceptable to you.

**An allogeneic (donor) transplant**

Very rarely, an allogeneic transplant may be an option for relapsed patients. An allogeneic transplant is a stem cell transplant using the stem cells from a matched donor, usually a brother or sister of the patient. Allogeneic transplants aim to use the immune system of a donor to help fight against a patient’s myeloma. This represents the main advantage of allogeneic transplants compared to autologous transplants (which uses patients’ own stem cells) – the donated stem cells have the potential to attack myeloma cells and prevent relapse. However, the risk of this procedure is that the donor’s immune cells also attack the patient’s healthy cells, leading to **graft-versus-host disease**, which can be serious and potentially life-threatening.

Currently, because of the risks involved, allogeneic transplants are not a part of routine treatment. They are generally carried out within a clinical trial or are done at the doctor’s discretion if a matched donor is available.

**Supportive care**

Due to the cumulative effects of the myeloma on the body and the ongoing exposure to the effects of treatment, treating relapsed myeloma involves much more than anti-myeloma treatment. Equal priority should be given to relieving and managing symptoms and complications with supportive treatments. For example, there may be a role for the following supportive treatments in your ongoing care at relapse:

**Radiotherapy**

Radiotherapy can be used to kill myeloma cells and to relieve pain in areas where there is damage caused by myeloma bone disease.

**Bisphosphonate treatment**

Bisphophonates are drugs that slow down or prevent bone damage. Bisphosphonate treatment is recommended for all patients with symptomatic or active myeloma. Some patients may have had a period off their bisphosphonate during the time they were in remission following initial treatment but bisphosphonate treatment will generally resume at relapse.
Other chemotherapy-based combination such as **DT-PACE** (a combination of six drugs) or **ESHAP** (a combination of four drugs)

A different drug/combination via a clinical trial

**Will new treatment make any existing side-effects worse?**

If you have persistent side-effects from previous treatment it is possible that further treatment will exacerbate this. For example, if peripheral neuropathy continues to be a problem for you following earlier treatment it may mean that you are not able to have certain other treatments at relapse that are also known to cause peripheral neuropathy. Your doctor will take all of this into account when discussing treatment options with you at relapse.

**Is treatment for relapsed myeloma effective?**

Relapsed myeloma can respond very well to treatment and go into another period of remission or plateau.

Your doctor or nurse should be able to tell you about average remission periods for the particular treatment combination you are on. This will be based upon evidence from clinical trials and their own experiences of using the treatment. There are many factors involved, however, and you may respond better or worse than the average.
Having said this, a shorter remission period is by no means a certainty. With newer drugs and treatment combinations becoming available all the time, some patients can achieve just as good a remission – or an even longer remission – from treatment at relapse as they did from their initial treatment.

What happens if treatment at relapse does not work?

Sometimes relapsed myeloma does not respond to additional treatment (i.e. it is refractory to this treatment). If your myeloma does not respond to the first treatment tried at relapse, your doctor will discuss the available options with you and you’ll decide together on the next steps. Many of the available drugs work in different ways so if you have not responded to one type of drug this does not mean you won’t respond well to a different type.

Just as was the case during your initial treatment, in order to find out how you are responding to treatment at relapse, tests will be carried out regularly (see Appendix for more details).

The signs that treatment is working include:

- A fall in the paraprotein or light chain level
- An improvement in symptoms and/or complications such as bone pain, anaemia and kidney function
- An improvement in your general health
- A reduction in the number of myeloma cells in the bone marrow

How you respond to treatment at relapse depends in part on how the myeloma has evolved at relapse. A greater number of myeloma clones more resistant to the effects of treatment may have built up within the bone marrow (see pages 16-18 for further explanation). The accumulation of side-effects from previous treatment can also limit the effectiveness of treatment, or you may have developed additional complications at relapse (e.g. kidney problems).

This can mean, unfortunately, that the remission period following treatment at relapse is shorter than after initial treatment.

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This can mean, unfortunately, that the remission period following treatment at relapse is shorter than after initial treatment.
Refractory is another word for resistant. Refractory myeloma is myeloma that develops resistance to treatment, or does not respond to it at all.

There are two types of refractory myeloma: ‘relapsed and refractory myeloma’ and ‘primary refractory myeloma’.

**Relapsed and refractory myeloma** is myeloma which initially responds to a treatment but then stops responding to it after a time, or myeloma which progresses within 60 days of receiving the last dose of treatment.

**Primary refractory myeloma** is myeloma that has not yet responded to any treatment.

These definitions are quite technical and are primarily used by doctors and researchers to standardise the descriptions of patients taking part in clinical trials. They are included here in case you hear your doctor referring to them.
Treatment options for refractory myeloma

Generally speaking, the same drugs and combinations available for relapsed patients set out in Section Five are also available to refractory patients. However, the treatment approach for refractory myeloma might be a little different than for relapsed myeloma due to the treatment resistance that has been identified. Doctors will try a number of different approaches to identify and overcome this which could include:

- Increasing the dose of one, some or all of the drugs within the combination to see if this encourages a response
- Adding in another drug to the treatment combination e.g. cyclophosphamide or dexamethasone, or an antibiotic called clarithromycin
- Changing to a different combination if the above does not work (this could be through a clinical trial)

Being refractory to a particular drug does not necessarily mean you will be refractory to all others; finding the right drug or combination may take a little time but is generally achievable in the majority of patients.

For all refractory patients psychological and emotional support is important, as knowing that they have not responded to treatment can cause understandable anxiety. Doctors and nurses will understand this is a difficult time for patients and will take time to talk through all of the available options.

See Section Seven for information on coping with the emotional and psychological aspects of relapsed and/or refractory myeloma.
It’s the news every myeloma patient dreads hearing – “it’s come back”, or, the treatment “isn’t working”. Some patients say in fact that being told their myeloma had returned or was not responding to treatment was as bad as being told their initial diagnosis.

Your mind may race ahead with worries about what’s going to happen to you, revisiting those early days following your diagnosis. Many of the strong emotions from around that time may be back – fear, sadness, anxiety, numbness, helplessness, to name only a few. Your emotions may swing from one extreme to the other or change from one day to the next; or you might feel extremely tired and not want to do very much at all.

“This was a very distressing time, although it wasn’t as bad as the initial diagnosis, for me. I did know that myeloma would return, although I had hoped it wouldn’t.”
Others may encourage you to be positive and to ‘fight’ the myeloma. For some people, adopting a fighting spirit enables them to cope with what is happening to them. But it’s hard to be positive all the time and pressure from other people can sometimes make you feel inadequate and guilty.

Adjusting to the news and learning to cope
Many patients experience some or all of the above feelings and reactions – all of which are normal responses to stressful circumstances – before reaching a point where they are able to start to take command of their situation.

You will have your own ways of adjusting and coping, but here are a few things to consider and keep in mind:

You are not alone. Relapsing and becoming refractory to treatment are realities of living with myeloma and more and more patients are living longer than ever before with relapsed and/or refractory myeloma.

There are many effective treatment options for relapsed and refractory myeloma. Many treatment options exist already, and new drugs are being developed and tested every day.

We all know that our myeloma will come back – obviously we all wish this takes as long as possible. When it does return, focus on what you can control – your thoughts, your actions.
Experience counts for a lot and will help you face any new challenges. For example:

- The knowledge that you have built up about myeloma will help you to take a more active role in your next treatment and care, if you want to, and may help to reduce any fear and anxiety.
- You will have a better idea of what to expect in terms of treatment side-effects as well as some strategies to reduce/cope with them.
- You have been building a relationship with your doctor and nurse since your diagnosis which should help ongoing communication.
- You know better who or what to turn to for support, such as support groups, Myeloma UK, particular family members or friends; and you’ll also know which stress-reducing activities work for you such as exercise, meditation or reiki.

There is room for hope and positivity. Your initial feelings may be negative, but once you adjust to the news, and with a little extra support, it’s possible for the negativity to give way to hope and positivity. Intense emotions will dissipate and life will settle down once more. However difficult things may seem, you can still have some control over how you manage your myeloma and learn to deal with the emotional and practical issues that it brings.

Seeking support
Difficult feelings may still be present at times. If you need help you can talk to your GP or specialist nurse who can point you in the right direction. For example, there may be strategies you can learn with support from a counsellor who specialises in working with cancer patients. Seeing a counsellor can give you the time and space to talk openly about your worries or things that you are unable to discuss with those closest to you.

"Remain positive and remember that there are treatment options available and new options to be explored."
Tips

■ Try to adopt a positive attitude but remember that it is OK to have ‘off’ days

■ Lean into those close to you – while they will be as upset at the news as you, they will have reserves of inner strength to help you both deal with what has happened

■ Try to plan to do something you enjoy every day. Simple things like a short walk with a friend or family member can make a difference to your mood

■ Take up or pursue hobbies that have until now been on the back burner

■ Be alert to side-effects of treatment and report these to your doctor or nurse so that they can be dealt with as soon as possible

■ Share your story with other patients either face-to-face or online – knowing others are going through a similar situation and what they do to cope can help

■ Consider taking up relaxing activities such as meditation, mindfulness, yoga or gardening

■ Plan a reward or treat for yourself for the end of each treatment cycle

There are also more specialised ‘talking therapies’ available which might be suitable, such as cognitive behavioural therapy (CBT). CBT can help manage your problems by changing the way you think and behave, and aims to find practical ways to improve your state of mind on a daily basis. Counsellors and CBT therapists may be based in your local hospital or in the community, and your GP and/or nurse will be able to arrange a referral for you.

Emotional, practical and social support is also available through centres such as Maggie’s and local support groups.

Remember, if at any time you have any questions or just want to talk through your feelings, you can call the Myeloma Infoline free on 0800 980 3332. You’ll also find support on our website www.myeloma.org.uk

Tips for living well with relapsed and/or refractory myeloma

In spite of the psychological impact relapsed and/or refractory myeloma can have, patients often talk of finding a ‘new normal’ where they have adjusted, to a degree, to their circumstances.

The following are some tips from patients who have been through what you are going through now to help you live well with relapsing and/or refractory myeloma:
If you are on a new treatment combination, learning more about it can help you to feel more in control. You can order information from Myeloma UK and keep up-to-date with the latest developments through our magazine *Myeloma Matters*, our website and Patient and Family Infodays across the UK.

If you work, let your employer know the situation as soon as possible – they can hopefully support you in making the adjustments to your working life that may be needed through your next course of treatment.

Discuss any planned or booked holidays with your doctor – they can advise you on the timings of treatment and whether this is likely to interfere with holiday dates.

Seek help if you are feeling very down or anxious – your healthcare team, counsellors, support groups and Myeloma UK are all here to support you.

"The ‘R’ words (‘relapsed’ and ‘refractory’) are the words you never want to hear. I heard them 15 months ago. However, with the advances that are being made in myeloma treatments, two months ago I heard the ‘R’ word we do all want to hear – remission! Never give up hope."
For some patients, myeloma becomes like a chronic illness – they have few relapses and they deal with symptoms and complications if and when they arise. For others, it's more difficult, with multiple relapses and short remission periods, and many courses of treatment needed to control their myeloma and its symptoms and complications.

How many relapses might I have and is there a limit to how many can be treated?

It is not possible to predict how many relapses a patient will have – this can vary enormously - and theoretically, there is no limit to how many can be treated.

However, you may work through all of the current treatments available on the NHS or on clinical trials. Similarly, persistent or serious side-effects may exclude further treatment, or limit its effectiveness.

Unfortunately, eventually relapses will occur with increasing frequency and the myeloma will become increasingly refractory to treatment. Most myeloma patients will eventually become refractory to all treatment. This may take many years or may take less time than this – this is very difficult if not impossible to predict.
Thinking about stopping treatment

You may reach a point when you decide not to have any more treatment for your myeloma, or a time is reached when the myeloma has progressed to a point where nothing more can be done to keep it under control. This may be because the myeloma is no longer responding to any treatment, or because the side-effects from treatment are significantly reducing your quality of life and you would prefer to have supportive care and symptom control only.

Making a decision to stop treatment is never an easy one. Planning ahead by having early discussions with your family, doctor and nurse can help to ease the process.

See our Planning ahead: an infopack for myeloma patients for more information
Myeloma patients can respond very differently to current treatment combinations. Some patients don’t respond well in the first place or they relapse quickly, despite having received the same treatment that, in other patients, leads to durable remissions, often many years long.

These differences in treatment responses are often matched by differences in the genetics of an individual patient’s myeloma – it is now clear that there isn’t just one type of myeloma, but multiple types, characterised by different genetic ‘clones’ that influence the response to treatment and speed of relapse.

With this knowledge, a number of different strategies are being researched to try to overcome relapse and, ultimately, find a cure for myeloma. These are discussed overleaf.
Drug research is also focused on further understanding the clonal evolution of myeloma cells which is responsible for the progression of myeloma. New technologies are allowing scientists to study the genetic changes in myeloma cells between when the disease is first diagnosed and when it relapses. This should allow the design of new drugs to prevent relapse and maintain long-term remissions.

Stratified or ‘targeted’ treatment
Stratified medicine is an approach that aims to tailor treatment specifically to an individual patient, for example based on the genetic subtype of myeloma they have. By giving treatment that is targeted to the specific genetic abnormalities of individual patients, in theory it should be possible to prevent relapse and transform myeloma into a chronic cancer.

Myeloma is currently in the first phases of stratified medicine, which has been already long-established in other diseases like breast cancer. Due to the increased understanding of genetic abnormalities that are associated with early relapse, and the availability of very powerful diagnostic tools to detect them, doctors and researchers are now testing stratified medicine approaches for high-risk myeloma patients in clinical trials.

Maintenance treatment
Currently various drugs are being investigated as maintenance treatment in myeloma. This is a continuous treatment approach which has the potential to prevent the growth of minimal residual disease and therefore prolong the time to relapse.

If maintenance treatment can be shown to generate longer periods of control of myeloma, both in newly diagnosed patients and in relapsed and/or refractory patients, myeloma will then have the potential to become a chronic cancer.

The safety and clinical benefit of maintenance treatment in relapsed patients is the subject of many ongoing clinical trials.

New drugs
Although myeloma currently remains an incurable cancer, patients are now living longer than ever before. This reflects the significant progress in drug development in myeloma over the past two decades, both in the expansion of existing classes of drug (for example new proteasome inhibitors such as ixazomib) and also the development of new drugs with entirely new ways of working (for example monoclonal antibody drugs such as daratumumab).
**Road to a cure**

The final goal is to develop treatment that will eradicate all myeloma cells. If all cells were eradicated, there would be no cells left to develop resistance to treatment. Achieving this would prevent the relapsing and refractory nature of myeloma and, it is hoped, lead to a cure.

The road to a cure is still long and likely to be bumpy. However, important steps are currently being made that will improve treatment for many patients in the near future and the continued investment in research and improvements to our understanding of the disease will hopefully herald further advances.
Anaemia:
A condition in which the amount of haemoglobin in the blood or the number of red blood cells is below the normal levels, causing shortness of breath, weakness and tiredness.

Antibody (immunoglobulin):
Proteins found in the blood produced by cells of the immune system, called plasma cells. Their function is to bind to substances in the body that are recognised as foreign, such as bacteria and viruses (known as antigens), enabling other cells of the immune system to destroy and remove them.

Biochemical relapse:
There is evidence of a relapse occurring in the blood (i.e. slowly rising paraprotein and/or light chain levels) but no evidence in terms of new or worsening symptoms or complications.

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

Bortezomib (Velcade®):
A type of proteasome inhibitor drug which is given either as an intravenous infusion or subcutaneous injection.
**Chronic:**
A disease that persists over a long period and causes continuous or episodic periods of ill health.

**Clinical relapse:**
There is evidence of a relapse occurring in both the blood (i.e. a steady rise in paraprotein and/or light chain levels) and from the emergence of new or worsening symptoms or complications.

**Complete response:**
The response to treatment which results in less than 5% plasma cells in the bone marrow, no detectable paraprotein, normal light chain levels and disappearance of any plasmacytomas.

**Depth of response:**
A measurement of the reduction in paraprotein or light chains in response to treatment.

**Disease progression:**
The term used when a disease continues to be active.

**DT-PACE:**
A treatment combination of dexamethasone, thalidomide, cisplatin, adriamycin, cyclophosphamide and etoposide.

**Duration of response:**
The length of remission or plateau before relapse.

**ESHAP:**
A treatment combination of etoposide, methylprednisolone (SH), cytarabine (Ara-C) and cisplatin.

**Fluorescence in situ hybridisation (FISH):**
A test used to detect chromosomal abnormalities in myeloma cells. It uses fluorescent probes to detect and localise the presence or absence of specific DNA sequences on chromosomes.

**Freelite® test:**
The brand name for the serum free light chain assay, a test used to detect and measure the type and amount of free light chains in the blood.

**Graft-versus-host disease (GVHD):**
A complication that can occur after an allogeneic stem cell transplant in which the newly transplanted donor cells attack the patient’s own tissue.

**Haemoglobin:**
The protein found in red blood cells that carries oxygen around the body.
**High-dose therapy:**
Treatment with high doses of chemotherapy given intravenously, usually via a central line (such as a HICKMAN® line), or a PICC line, prior to patients receiving healthy stem cells as part of the stem cell transplantation procedure. Also known as conditioning treatment.

**Hypercalcaemia:**
A higher than normal level of calcium in the blood, which may cause loss of appetite, nausea, thirst, fatigue, muscle weakness, restlessness and confusion.

**Immune system:**
The complex group of cells and organs that protect the body against infection and disease.

**Immunomodulatory drug:**
A type of drug used to act on the body’s immune system.

**Lenalidomide (Revlimid®):**
A type of immunomodulatory drug which is given orally.

**Maintenance treatment:**
Further treatment which is given over an extended period of time after the main treatment has finished, often at a lower dose, to prolong remission/plateau.

**Malignant:**
A term for cancerous cells which have the ability to spread.

** Minimal residual disease:**
The term used to describe the level of myeloma cells that remain when the patient is in remission.

**Monoclonal antibody drugs:**
A type of synthetic drug that mimics the actions of antibodies.

**Next-generation sequencing:**
A DNA sequencing technology that allows the study of genetic changes in myeloma cells in immense detail.

**Non-secretory myeloma:**
A type of myeloma in which there is no detectable paraprotein or light chains in either the blood or urine.

**Panobinostat (Farydak®):**
A type of histone deacetylase inhibitor drug which is given orally.

**Paraprotein:**
An abnormal antibody (immunoglobulin) produced in myeloma. Measurements of paraprotein in the blood can be used to diagnose and monitor the disease. Also known as M protein.
Peripheral neuropathy:
Damage to the nerves that make up the peripheral nervous system causing pain, tingling and altered sensation.

Plasma cells:
A type of white blood cell that produce antibodies (immunoglobulins) to fight infection.

Plateau:
A period of time when the myeloma, and the paraprotein level, is relatively stable.

Pomalidomide (Imnovid©):
A type of immunomodulatory drug which is given orally.

Prognosis:
The probable outcome or course of a disease.

Proteasome inhibitors:
A type of drug which interferes with the normal functioning of part of a cell called the proteasome. Myeloma cells rely more heavily on proteasomes than normal, healthy cells; proteasome inhibitors therefore cause myeloma cells to die while leaving healthy cells less affected.

Remission:
The period following treatment when myeloma cells and paraprotein are no longer detectable, and there are no clinical symptoms of myeloma.

Stem cell transplantation:
The infusion of healthy stem cells into the body. This allows the bone marrow to recover and renew its blood-forming capacity following the administration of high-dose chemotherapy.

Stratified treatment:
A treatment approach that aims to tailor treatment specifically to an individual patient, for example based on the genetic subtype of myeloma they have.

Thalidomide:
A type of immunomodulatory drug which is given orally.

White blood cells:
A type of blood cell involved in the body’s immune system, which help to fight infection and disease.
Appendix – Tests carried out to help diagnose a relapse

Blood tests
There are a variety of blood tests carried out at your regular appointments that help to monitor the activity of your myeloma and identify when you may be relapsing or refractory to treatment.

Paraprotein or light chain measurement
Changes to your paraprotein and/or light chain level can be good indicators of changes in the activity of your myeloma. If your paraprotein and/or light chain levels rise over the course of two or three subsequent blood tests, this may be an indication that your myeloma is relapsing or becoming refractory to treatment.

Increasingly, light chain levels are measured in all myeloma patients alongside more conventional blood tests. This is because light chains are elevated and measurable in the vast majority of myeloma patients and at an earlier stage than paraprotein levels are measurable. This means that the highly sensitive Freelite® test, which measures light chains, has the ability to detect changes in the activity of the myeloma sooner than conventional blood tests. This helps to detect relapsed or refractory myeloma earlier.

Doctors will also be looking at other blood results to get an overall picture of your situation, as they too will give an indication of whether the myeloma is returning.

Infoline: 0800 980 3332
**Full blood count**
A full blood count measures the levels of the different cells in your blood. The most important are:

- **Red blood cells** – a low count means a reduction in the oxygen-carrying **haemoglobin** levels. This can lead to anaemia.
- **White blood cells** – low counts of some or all of the different white blood cells indicate that you are at a greater risk of infection.
- **Platelets** – a low count shows that you are at an increased risk of bleeding or bruising more easily than normal.

**Blood chemistry**
A full blood chemistry test provides an overview of the levels of various substances in your blood that can indicate that your myeloma is becoming active again and the presence of myeloma-related complications. They include:

- **Creatinine and urea** – both are waste products that are normally filtered out by the kidney and passed into the urine. High blood levels of creatinine and urea indicate poor kidney function.
- **Calcium** – a mineral which is normally found in bone. In patients with active myeloma bone disease, calcium is released from the bone into the blood leading to higher than normal levels (hypercalcaemia).

### Blood tests and normal ranges

<table>
<thead>
<tr>
<th>Blood tests</th>
<th>Test name</th>
<th>Normal range*</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full blood count</td>
<td>White cell count</td>
<td>4.0 - 11.0 (x 10⁹/L)</td>
<td>A low count makes you less able to fight infections</td>
</tr>
<tr>
<td></td>
<td>Haemoglobin (men)</td>
<td>135 - 180 (g/L)</td>
<td>A low haemoglobin level causes anaemia and fatigue</td>
</tr>
<tr>
<td></td>
<td>Haemoglobin (women)</td>
<td>115 - 160 (g/L)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Platelets</td>
<td>150 - 400 (x 10⁹/L)</td>
<td>A low count makes you bruise or bleed easily</td>
</tr>
<tr>
<td></td>
<td>Absolute Neutrophil Count</td>
<td>1.5 - 7.5 (x 10⁹/L)</td>
<td>A low count makes you less able to fight infection</td>
</tr>
<tr>
<td>Urea, electrolytes and creatinine</td>
<td>Urea</td>
<td>2.5 - 6.7 (mmol/L)</td>
<td>Measure of kidney function</td>
</tr>
<tr>
<td></td>
<td>Creatinine</td>
<td>70 - 150 (μmol/L)</td>
<td>Measure of kidney function</td>
</tr>
<tr>
<td></td>
<td>Calcium (total)</td>
<td>2.12 - 2.6 (mmol/L)</td>
<td>Raised by myeloma bone disease</td>
</tr>
<tr>
<td>Proteins</td>
<td>Paraprotein</td>
<td>0 (g/L)</td>
<td>Abnormal protein found in certain conditions, including myeloma</td>
</tr>
<tr>
<td></td>
<td>Total protein</td>
<td>60 - 80 (g/L)</td>
<td>Often raised in myeloma because of amount of paraprotein</td>
</tr>
<tr>
<td></td>
<td>Albumin</td>
<td>35 - 50 (g/L)</td>
<td>Often lowered in myeloma because of presence of paraprotein</td>
</tr>
<tr>
<td></td>
<td>Kappa (κ) light chain</td>
<td>3.3 - 19.4 (mg/L)</td>
<td>Part of an immunoglobulin (antibody). Levels are often raised in myeloma, with an abnormal ratio (normal ratio is 0.26κ to 1.65λ)</td>
</tr>
<tr>
<td></td>
<td>Lambda (λ) light chain</td>
<td>5.71 - 26.3 (mg/L)</td>
<td></td>
</tr>
</tbody>
</table>

* The normal range is an average, but each hospital laboratory has its own ‘normal range’ of values.

**Explanation of units**
- **g/L** number of grams there are in a litre of blood
- **x 10⁹/L** number of billion cells there are in a litre of blood
- **mmol/L** number of thousandths of a mole** number of millionths of a mole** there are in a litre of blood
- **mol** a standard measurement for the amount of any chemical

Please note that doctors do not use a litre of blood to make these measurements; they just take a small sample (a few millilitres) and then multiply up the results.

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Infoline: 0800 980 3332
Imaging tests
X-rays may be repeated if relapse is suspected and you are experiencing any new or worsening bone pain. If there is any doubt about the results of the X-rays, you may be asked to undergo more sophisticated imaging scans such as a magnetic resonance imaging (MRI) or a computerised tomography (CT) scan of an area causing concern. These scans can provide more detail and identify areas of bone damage that are not so easily detected by X-ray.

Bone marrow tests
Sometimes, a repeat bone marrow biopsy is performed to help determine a relapse. This would only be in the context of ambiguous or contradictory symptoms or blood test results, or perhaps if you are taking part in a clinical trial. Patients with non-secretory myeloma generally also have to have regular bone marrow biopsies to determine response to treatment and relapse.
Myeloma UK is the only organisation in the UK dealing exclusively with myeloma. Our research programme and Clinical Trial Network are accelerating the discovery, development of and access to new treatments. Our patient services are helping patients and their families cope with everything a diagnosis of myeloma brings.

We are helping myeloma patients to live longer and with a better quality of life.
About Myeloma UK

Myeloma UK is the only organisation in the UK dealing exclusively with myeloma.

With Myeloma UK you can...

Call our Myeloma Infoline for practical advice, emotional support and a listening ear:
UK: 0800 980 3332
Ireland: 1800 937 773

Find your nearest Myeloma Support Group to meet up and talk to other people face to face.

Read Myeloma Matters, our quarterly magazine, which offers a mix of the latest news in research and development for myeloma, and patient and family experiences.

Myeloma TV

Visit www.myeloma.org.uk, a one-stop-shop for information on myeloma; from news on the latest research and drug discovery to articles on support, treatment and care.

Watch Myeloma TV which hosts videos about myeloma presented by experts, patients and family members.

Use the Discussion Forum for the opportunity to share experiences and advice about living with myeloma.

Find us on Facebook and Twitter search for myelomauk

Infoline: 0800 980 3332
Information available from Myeloma UK

Our information covers all aspects of myeloma which we group into six categories. An outline of what the publications within each category cover is given below:

<table>
<thead>
<tr>
<th>Essentials</th>
<th>These titles give an overview of myeloma, its treatment and management. Particularly useful for newly diagnosed patients and their families.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatments and tests</td>
<td>This series provides information about the range of treatments and tests used in myeloma.</td>
</tr>
<tr>
<td>Symptoms and complications</td>
<td>These publications cover the most common symptoms and complications of myeloma such as myeloma bone disease and fatigue.</td>
</tr>
<tr>
<td>Clinical trials and novel drugs</td>
<td>This series gives information on many of the promising drugs currently being investigated for the treatment of myeloma in clinical trials.</td>
</tr>
<tr>
<td>Living well with myeloma</td>
<td>These titles provide information relating to living well with myeloma such as diet, managing finances, travel insurance and caring for someone with myeloma.</td>
</tr>
<tr>
<td>Related conditions</td>
<td>Publications on conditions related to myeloma, including MGUS, plasma cytoma, smouldering myeloma and AL amyloidosis.</td>
</tr>
</tbody>
</table>

For a full publication list visit www.myeloma.org.uk/publications
To fill in a short survey about our patient information online, please go to www.myeloma.org.uk/pifeedback

Other publications

Patient diary
This diary helps patients keep a track of hospital appointments and key test results in a practical, simple way.

The small things that make all the difference
Hints and tips written for people affected by myeloma, by people affected by myeloma.

Children’s book about myeloma
Kelsey and the Yellow Kite tells the story of how a little girl learns to understand about her dad’s myeloma.

Myeloma A – Z
A booklet which explains key terms relating to myeloma.

Our information and publications are free and available to order by phone. You can also download or read online. Email: askthenurse@myeloma.org.uk

Call 0131 557 3332
www.myeloma.org.uk

Infoline: 0800 980 3332
For more information about myeloma and Myeloma UK contact:

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[www.myeloma.org.uk](http://www.myeloma.org.uk)