Juvenile Dermatomyositis (JDM) -
What does it mean for my child?
(Frequently Asked Questions and Answers for parents of children with JDM):

GENERAL

What is Juvenile Dermatomyositis?
- Dermatomyositis is an illness (disease) that we call ‘autoimmune.’ Autoimmune means that a group of cells that normally protects the body from infection (germs) actually turn against it and fight it instead. This damages the body instead of protecting it. We do not know exactly why this happens.
- An autoimmune reaction causes inflammation (pain / redness / swelling) in body parts when there is no infection present. In dermatomyositis, the inflammation is in very small blood vessels in muscle (myositis) and skin (dermatitis). This inflammation leads to the problems that your child may have experienced such as muscle weakness, or pain and skin rashes on the face, above the eyelids, on the knuckles, knees and the elbows.
- Dermatomyositis may start in children and in adults. If the symptoms appear before the age of 16 years, we call the disease ‘Juvenile’ Dermatomyositis (JDM).
- Some children / young people may have muscle inflammation without a rash or skin problems. In some cases, a rash can occur later but a small number of children / young people never have skin problems and their disease is called juvenile polymyositis (JPM). This is like dermatomyositis and most of the information on this FAQ sheet is for both. Not having a skin rash can make it hard to know if your child has the illness. Your child’s hospital doctor will carry out tests to make sure that there are no other reasons for the muscle weakness and that your child does have JDM or JPM.

How common is JDM?
- JDM is a very rare illness in children. It affects approximately four children in every million each year.
- Girls are twice as likely as boys to get it.
- The illness usually starts between the ages of four and ten, but children of any age can be affected.

What causes JDM?
- As with most autoimmune diseases the cause of JDM is unknown. Many doctors and researchers across the world are looking at JDM in detail and are trying to find what causes it.
- There is likely to be a genetic (hereditary) factor to all autoimmune diseases. We know some of the genes (messages that are passed on from parents to children) are more common in children with JDM than children without the disease but these do not explain the whole story.
- We think autoimmune diseases start due to contact with a ‘trigger’, which makes the body’s immune system overreact. Research has not yet identified one specific trigger but it is thought that triggers could include viruses or an environmental factor (such as sunlight).

Why my child? Is it my fault?
- JDM occurs by chance. It is not your fault or your child’s fault. It is not something that you or your child has done (or not done) to make them have JDM.

Is JDM an inherited disease?
- JDM is not an inherited disease in that it is not passed down directly from a mother / father to their child. There do seem to be some genes / genetic factors (messages passed from parents to children) that make a person more likely to develop an auto-immune disease but this does not mean that every individual with these genes will develop an autoimmune disease.
- The disease is likely to be multi-factorial. This means that many factors can contribute to somebody getting JDM. We think that in most cases a ‘trigger’ is needed to cause JDM in a child who is more likely to get the disease due to genetics factors. Triggers may include infections or sunlight.
- Some children with JDM have relatives with other auto-immune diseases such as diabetes, thyroid disease, lupus or arthritis. Since JDM is so rare, it is very unlikely that two members of one family will have the disease. Likewise, it is very unlikely that a person with JDM will go on to have children with JDM.

Is it contagious?
- JDM is not contagious so it cannot be caught or passed on from one person to the next.
Can JDM be prevented?

- As the cause of JDM is not yet known, we do not know how or if JDM can be prevented. If we were to find out the cause then maybe we could advice on how to prevent the disease. Research into the cause of JDM is ongoing.

Is dermatomyositis different in children than in adults?

- Yes, it is. When the disease is seen in adults, the start and progress of the disease is different than that of the childhood (juvenile) form. In adults who have dermatomyositis, there can be an association with malignancy (cancerous cells). This does NOT tend to be the case in children with JDM. Adults may also have positive blood tests (myositis specific antibodies) that are not always seen in children. Children may have different antibodies than adults.
- These differences suggest that the underlying illness is different. In children, the illness can start suddenly like in adults. However many children become unwell gradually. Over time they may develop tiredness or temperatures and other complaints such as joint pains or swelling of their joints. Children are unlikely to have problems with their heart or lungs due to JDM whereas adults can.
- Polymyositis, where there is muscle involvement without any skin changes, is more frequent in adult disease but is very rare in children.
- It is not unusual for children to have features of other auto-immune diseases such as arthritis, scleroderma or lupus as part of their JDM. This is called an ‘overlap’ syndrome. In adults, disease patterns tend to be more specific and overlap is less common.
- Because we see differences in adult and childhood dermatomyositis, it is important for children to be seen by professionals that specialise in looking after children with JDM.

SIGNS AND SYMPTOMS

What are the signs and symptoms (complaints) of JDM?

The main symptoms (complaints) of JDM are as follows:

- Weak, painful muscles: The muscles that tend to be affected the most are those near the trunk (central part) of the body. These include the upper arms, the thighs, the neck and the trunk itself. However, JDM can affect any muscle in the body. Children may experience swallowing difficulties or may develop changes in their voice (sometimes described as a ‘nasal’ voice). Children may have difficulty getting up from bed, climbing up stairs and getting up from the floor or a chair.
- Skin rashes: The typical rash that we see in children with JDM usually occurs on the face, knuckles, elbows, knees and ankles. Rashes can become worse in sunlight. This means that they are photosensitive. JDM rashes may not appear at the same time as the muscle weakness, they can appear before or even after. The following is a description of common rashes or other skin changes associated with JDM:
  - On the eyelids the rash appears as a red, purplish colour. This is called a ‘heliotrope rash.’
  - On the face, the rash appears as a reddened area on both cheeks and can cross the nose. This is called a ‘malar rash.’
  - Across the knuckles, elbows and knees, the rash looks like red / violet, dry skin patches. These are called ‘Gottron’s patches.’
  - The tiny blood vessels at the base of the fingernails may turn a pinkish colour or become more obvious. These are called ‘nail-fold capillary changes.’
  - Children may get swelling to the face or body, particularly around the eyes, due to watery fluid building up in the tissues. This is called oedema and when it occurs across the eyes, it is called ‘peri-orbital oedema.’
  - Some children can develop small hard lumps under the skin or in the muscle that are due to calcium being deposited. This is called ‘calcinosis.’ These lumps can break through the skin (ulcerate) and leak a thick milky white fluid (calcium). If this happens there is a chance of the lumps becoming infected. Calcinosi can be a sign of active disease or ongoing inflammation (redness, pain, swelling). These lumps are more common when the disease has been there a long time. This is a sign that the disease needs aggressive treatment.
  - Sometimes fatty tissue can waste away in JDM. This is called lipodystrophy.
- Fatigue, tiredness: Children with JDM may become tired easily. Exercise, like walking or running, may become increasingly difficult. They may need to take frequent rests and it may become harder for them to keep up with their friends. Concentration and memory may also be affected when the illness is active.
- Other symptoms (complaints) that some children may have include the following:
  - Irritability (commonly seen in children with active disease, particularly in younger children).
  - Joint pain (‘arthralgia’) and / or swelling or stiffness in the joints (‘arthritis’).
- Fever (temperatures).
- Mouth ulcers.
- Headaches.
- Hair thinning or hair loss (this is called alopecia).
- Change of colour of the hands in the cold (this is called Raynaud’s phenomenon).
- Chest pain.
- Abdominal (tummy) pain and/or bowel problems (such as diarrhoea or blood in the stool).

It is unlikely that your child will experience all of the above symptoms (complaints).

**Is JDM the same in all children?**
- JDM can be a very variable illness. It can range from being mild, where children may have few symptoms (complaints) and it barely affects them, to more severe disease, where it makes living a normal life much harder.
- Sometimes JDM can affect the organs of the body (such as the heart, lungs, brain) as well as the muscles and skin. Organ involvement in JDM can vary from child to child.
- When JDM affects children’s organs such as heart, lungs, abdomen (gut) or brain, treatment needs to be given quickly. Even if a child has very mild disease it is usual to treat them with medicines to prevent any complications (problems) in the future (such as calcinosis or reduced movement of a joint).
- There are some cases of JDM where the child will not have any muscle weakness at all and will just have skin changes (we call this amyopathic dermatomyositis). Others will just have muscle disease without any skin disease (polymyositis). Sometimes the rash can appear later than muscle weakness in JDM.

**How can I tell how severe my child’s disease is?**
- The doctor looking after your child will be able to tell you how severe your child’s illness is. Because JDM is so rare, your child’s GP is unlikely to have had experience of this illness and so it is best for you to talk to your child’s specialist.
- Most children with dermatomyositis will be under the care of a paediatric rheumatologist, neurologist or dermatologist.

**Can children have JDM without having a rash?**
- Yes. Some children may just get muscle involvement without any skin rashes. We call this Juvenile Polymyositis.

**INVESTIGATION/DIAGNOSIS**

**What happens when my child is diagnosed with JDM?**
- A team of people will be there to look after your child and will make them feel better. This team is likely to include doctors that specialise in JDM, specialist nurses and specialist physiotherapists. Your child may also see other professionals as part of a team including occupational therapists, psychologists and pharmacists.

**What laboratory tests are done in JDM?**
- Blood tests help in the diagnosis of JDM in combination with other specialist tests. Taking blood tests over time help us to work out how active or quiet your child’s illness is. Blood tests are also used to monitor medicines. Although there may be many blood tests taken, this can usually be done on one sample at each clinic visit. Your child will be offered a gel to numb the skin before having blood tests to prevent the needle causing pain.
- Blood tests that are commonly taken are as follows:
  1. **Muscle enzymes (such as CK, LDH).** When muscles are inflamed, they can become ‘leaky’ so that muscle enzymes (substances that start chemical reactions) leak into the blood. Blood tests show that the muscle enzymes are high, particularly early in the illness. Later in the illness however, it is possible for the disease to be active but the muscle enzymes to be normal.
  2. **Liver function tests (AST, ALT).** Although these tests traditionally are associated with problems in the liver, they can also be high due to muscle inflammation (even if the liver is normal).
  3. **Full Blood Count (FBC).** This counts the number of cells in a sample of blood, including haemoglobin (this carries oxygen around the body), white cells (blood cells that fight infection and are important in
inflammation) and platelets (a blood particle important in clotting). Haemoglobin (Hb) can be low in JDM due to anaemia whereas white cells and platelets can be high due to inflammation.

4. **Anti-nuclear antibody test (ANA) or other antibody tests.**
   Antibodies are proteins, produced by blood cells, which normally circulate in the blood to defend against foreign invaders such as bacteria, viruses, and toxins. Sometimes, the body can produce antibodies against its own cells. We can do blood tests to look for particular antibodies associated with JDM, these include ANA and more specific antibodies (some of which are only available at the moment as part of research studies). Although antibodies like ANA can be detected in the blood in JDM, they are not specific and they may be seen in other auto-immune diseases. Likewise, somebody may not have these antibodies and still have JDM.

**What other tests will be performed?**
To help with the diagnosis of JDM, the following tests may also be done:

- **MRI scan of muscles:** An MRI scan consists of a large tube with powerful magnets. Your child will need to lie still in this tube for approximately 20-30 minutes for pictures to be taken of the thigh muscles. The scan does not hurt but it is quite noisy.
- **X rays:** These may be taken of the chest or joints. They may also be taken to look for calcinosis in the arms or legs
- **ECG and ECHO cardiogram:** These tests look at the function of the heart. Neither test hurts. An ECG involves sticking some leads to the chest using sticky plasters and monitoring how the heart beats. An echocardiogram involves an ultrasound of the heart. (Women have ultrasounds of their tummy when they are pregnant). The scan does not hurt but the jelly can feel a bit cold.
- **Abdominal Ultrasound:** This is a scan of the tummy. The scan does not hurt, but the jelly may feel a bit cold.
- **Lung function tests:** These tests look at how well the lungs work. This is done by blowing into a special machine.
- **CT scan:** Some children will need a CT scan of their chest. This involves lying still in a tube (a bit like an MRI) for a short period of time. It does not hurt.

Some children will need a **Speech and Language Therapist** to assess the way that they swallow. In some cases, an X-ray test is used to assess swallowing (**video fluoroscopy**). This involves swallowing some liquid whilst x rays are taken.

- **Muscle biopsy:** It may be necessary to take a very small bit of muscle from the top of the leg to look at under a microscope. This is usually done asleep under a general anaesthetic.
- **Skin biopsy:** A small sample of skin may be taken to look at under a microscope. This can be done at the same time as a muscle biopsy or at a different time.
- **EMG:** This looks at the function of muscles. It is done by inserting small needles called electrodes into the muscles to measure its electricity. It may be done in some children to determine if there is a problem with the muscles or not.

How often are tests done? What happens in clinics?

- Blood tests are usually carried out when attending clinic. Blood tests are used to monitor the illness and also the medicines that your child will be taking. Although your child may need blood tests more frequently at the start of your illness, in time, they may only need to be taken 4 times a year (or less if they are not taking any medication).
- When attending clinic your child will be seen by their doctor. They may also see a physiotherapist and a nurse. They will be asked questions about how they have been feeling since their last clinic appointment. The doctor will then examine them and will want to listen to their heart and lungs, feel their tummy and examine their joints. The doctor / physiotherapist / nurse will also want to see how strong they are and they may test muscle strength in the arms, legs, neck and tummy.
- If your child has a flare (worsening) of their disease, they may need to undergo more investigations such as an MRI, X-rays or investigations of their heart (ECG / ECHO), or lungs (lung function tests or a CT scan).

How can I be sure that it is definitely JDM?

- The doctor will look at the results of all tests to work out if your child has JDM. If your child does have JDM, they will be started on treatment. Your child may need more investigations if they do not respond as well as expected to treatment, or the treatment may need to be changed.
How will my child get better?

- There are medicines to help your child get better. The treatment is aimed at reducing inflammation in the body and avoiding a flare (worsening) of your child’s JDM. The treatment that is given may change from time to time. This will depend on how JDM is affecting your child. It is very important that the prescribed medicines are taken regularly. Medicines for JDM work in the background over time and so although your child may not notice a difference if one dose is missed, the medicines will not work as well if several doses are missed.
- Your child’s doctor or nurse will explain which medicines can help. They will explain the drugs to your child and to you, and can also provide written information to take away.
- All the medicines used to treat JDM decrease activity of the immune system. As a group, they are called ‘immunosuppressants.’ Each drug suppresses the immune system to a greater or lesser degree. Therefore, your child may be more at risk of infection and you should seek medical advice if your child becomes unwell. Some vaccinations cannot be given whilst on these medicines.
- Here are some of the drugs that may be used. NB: This is not a complete description of the drugs and side effects and your child should be given information by your specialist doctor or nurse.

Steroids:

**Prednisolone:** This is the most effective drug for controlling JDM initially because it works quickly. It is a steroid but not the same kind of steroid drug that some body builders take. This drug works to decrease the inflammation (redness, pain, swelling) caused by JDM. Side effects of prednisolone are related to the dose taken and how long it is taken for. When your child is diagnosed a high dose will usually be required. As your child’s JDM improves, the dose will be lowered gradually and any side effects experienced will get less and disappear. Side effects that may be noticed include increase in appetite, increase in weight, a “puffy face,” acne, mood swings, stretch marks, increased risk of infection, slower growth and increased body hair. In the long term your child may develop weaker bones (but there are now treatments to prevent this), high blood pressure or cataracts (a cloudy area that develops in the lens of the eye. These are different from the cataracts seen in older people and usually do not affect vision). You may feel anxious about your child taking prednisolone after reading the above side effects; however it is the best drug initially for treating JDM. Doctors would not prescribe it if the illness could be treated in a better way. Side effects are dose related (more likely to occur if higher doses are given for a long time) and doctors will always use the lowest possible dose to get your child better. It is very important to wait until the doctor guides your child about reducing the steroid dose. Prednisolone should NEVER be stopped suddenly. This may make your child extremely sick. The doctor will reduce your child’s prednisolone gradually guided by symptoms present and blood tests.

**Methyprednisolone:** This drug is similar to prednisolone except it is given into a vein in your child’s arm. It is often given in the early stages of JDM when it is more active or may be given in times of disease flare (worsening).

**Disease Modifying Anti-Rheumatic Drugs (DMARDS):**

Treatment with steroids is usually associated with use of other drugs that treat JDM by suppressing (decreasing) the immune system. These drugs are called ‘Disease Modifying Drugs.’ The most common drug used in addition to steroids is methotrexate. Although this works very well in 70-80% of children with JDM, some children will need alternative medicines. Different DMARDS are used in severe disease to those used in mild disease. Methotrexate and many other DMARDS take at least 6-8 weeks to start to take effect and so steroids need to be used first to control JDM. All DMARDS work by suppressing the immune system in some way, and so they can make your child prone to infections. This is not usually too much of a problem, but you need to seek medical attention sooner than you would if your child were not on these medicines. Some vaccinations cannot be given whilst taking these drugs. You may need to stop your child’s DMARD medicine (but NOT steroid) temporarily if your child is unwell with a temperature. You should seek advice from your doctor or nurse specialist if unsure.

**Methotrexate:** This drug reduces inflammation (redness, pain, swelling) by acting directly on the immune system. It is usually given over a longer period of time and helps to maintain remission (keeping the disease quiet) when reducing the steroid dose. Methotrexate can affect the white blood cells, which fight infection, and also the liver tests, so regular blood tests are required. Methotrexate has been used for many years and tends to be the first treatment given for most patients with JDM in addition to steroids.

Other medicines that may need to be used instead of methotrexate or in addition to methotrexate are as follows:

**Ciclosporin:** Like methotrexate, this is usually given over a longer period of time. Long term side effects
include raised blood pressure, increase in body hair, gum enlargement and kidney problems.

**Azathioprine:** This drug helps to reduce inflammation by suppressing the immune system and like other DMARDS, regular blood tests are needed. It can sometimes cause sickness or rashes.

**Mycophenolate Mofetil (MMF):** This drug also suppresses the immune system and therefore regular blood tests are required. MMF can cause diarrhoea when it is first given. For this reason, it is usually started in a low dose and increased over a few weeks.

**Hydroxychloroquine:** This is a milder medication that can be given in addition to drugs such as methotrexate. It can be particularly good at helping skin disease or joint aches and pains. If your child is taking hydroxychloroquine, they should have an eye test with an optician once a year since it can (rarely) cause changes in colour vision or peripheral vision (seeing objects outside the direct line of vision). This usually recovers once the drug is stopped.

**Immunoglobulins (IVIG):** This contains human antibodies (proteins) concentrated from blood. It is given through a vein in your child’s arm. IVIG works through the immune system, helping the inflammation. It is usually given in addition to other medicines such as methotrexate and can be useful for skin disease or generally decreasing inflammation to allow steroid doses to be reduced.

**Infliximab:** This is given through a vein in your child’s arm. Like most of the other medicines this works by reducing inflammation and regular blood tests are required whilst on infliximab. Infliximab is a type of medication called a biologic that targets the immune system in a more specific way. It tends to be given as an extra treatment in those children that do not respond well enough to initial medication with drugs such as methotrexate.

**Cyclophosphamide:** This is a powerful immunosuppressive drug that helps decrease the activity of cells causing inflammation. It is usually given once a month through a vein in your child’s arm and requires a brief overnight stay in hospital. Cyclophosphamide is usually only given in more severe cases of disease and is needed when there is organ involvement (eg. lungs, brain) or severe skin or muscle changes.

**Rituximab:** This is also an immunosuppressive drug used in severe disease and usually is given after other drugs have been tried. It is given through a vein in your child’s arm. Two doses are usually given two weeks apart and then may need to be repeated at a later date.

**Are there things that I can do to help my child’s JDM?**
There are things that you can do to help your child in addition to encourage them to take their medication

**Sun protection:** Sun protection is important because sunlight can make JDM rash worse or can trigger a flare (worsening) of the disease.
- Encourage your child to use sunscreen with a sun protection factor (SPF) of 50 or more. Be sure to apply 30 minutes before going out even on cloudy days and do not forget to use on the ears. Find a preparation that best suits your child as some rub in better than others.
- Protect exposed areas with a hat and long sleeved shirts.
- Sometimes the rash may be affected by artificial lighting such as fluorescent, halogen and LED lights, so do check whether lighting in the home or school could be affecting your child. If so, then it could be filtered or the bulb strength reduced.

**Medications:** It is important that your child remembers to take their medication as prescribed by the doctor, even when they start to feel better. The doctor will gradually reduce the steroid dose. It is very important that these instructions are followed as stopping steroids suddenly can be dangerous.

**Fatigue and pacing:** Tiredness is very common in JDM. Your child may have a limited pot of energy and so it is important that they pace themselves and do not take part in activities until exhausted. Your child should ask for help when needed. It is all about taking things at a steady pace and gradually increasing activity over time.

**Exercise:** Exercise is always important, but during a flare (worsening) of JDM it may be very difficult to do exercise. As common symptoms of JDM are muscle weakness and joint stiffness, these result in a reduction in mobility and fitness. These difficulties may be helped through regular physiotherapy sessions. The physiotherapist will teach your child stretching, strengthening and fitness exercises. These exercises are designed to build up muscle strength and stamina (sustaining energy or strength over a long period) and to
improve and maintain the range of movement of the joints. You can help to encourage your child to do their physiotherapy exercises. Once your child is feeling better then it is important to get back to doing regular exercise taking things at a steady pace to gradually increase exercise tolerance.

**Diet:** No special diet will cure or prevent a flare (worsening) of JDM. A well-balanced diet that includes a variety of foods is recommended. Remember that prednisolone can cause your child to feel hungry and this increase in appetite is not your child’s fault. Trying to replace crisps and sweets with fruit, vegetables, nuts and seeds may help to slow down any weight gain.

**Sleep:** Your child may feel more tired than usual due to JDM. This will improve over time with treatment. A regular sleeping pattern and routine to your child’s day will help.

**Vaccinations:** When your child is taking immune-suppressive medications such as steroids, DMARDs or biologics, they will not be able to receive live vaccinations (those vaccinations containing a weakened live virus). These include MMR, BCG and some travel vaccinations. However, your child can receive killed vaccinations (prepared from dead infections) and these should be given at the appropriate age. In addition to this, when your child is taking medicines that suppress the immune system, we recommend a flu vaccination for them and other family members every year. Children should also have a pneumococcal vaccination (to prevent pneumonia) every 5 years. You can ask your specialist doctor or nurse about any vaccinations that you are not sure about.

**How long are children with JDM on treatment for?**
- Each child / young person is different and the length of drug treatment will depend on the characteristics of the disease in the individual child. For some children the disease may be short lived, whilst others may have the disease for many years.
- Doctors aim to control the disease so that your child can lead a normal life and do everything that they wish to do. Treatment would usually only be stopped after your child has not had any symptoms (complaints) of JDM for some time (usually at least 1 year with no complaints). JDM is a disease particularly sensitive to drug treatment reductions. This means that if drugs are reduced too fast, it can cause a flare of the disease. Your child should only reduce medication on the advice of your specialist team.

**Are there any alternative/ complimentary therapies for JDM?**
- Complimentary or alternative therapies are those that fall outside the conventional medicine. They can be based on cultural or historical traditions rather than scientific evidence. Some complimentary therapies are safe and can be used in addition to your child's medication. However it is important to consider all implications and advice given from unqualified staff. Some herbal remedies can interact with prescribed drugs and increase risk of side effects. It is highly recommended that you seek the advice of your specialist before using complimentary / alternative remedies.

**PROGNOSIS (LONG TERM OUTLOOK)**

**What is the long term outlook for children with JDM?**
- Some children will have just one episode of JDM, which may last for 2-3 years and then goes away (enters what is called ‘remission’). Other children will have disease that comes back after a prolonged period of remission. Some children have a more prolonged disease than can last many years (‘chronic course’).
- It is important for the disease to be treated aggressively by specialists in JDM. When this is done, the outlook is overall favourable.

**Will this ever go away?**
- The disease will become quiet with treatment, so that your child will be able to carry out all of the activities that they want to do. Initially this will be with your child taking medicine, but ultimately without medicine.
- When the disease is quiet / gone, we call this remission. There is a small chance that the disease will come back even after long periods of remission, but it can be treated if this happens and it does not tend to be as bad as when it first presents.

**Will the rash ever go away?**
- Yes, the rash will go away. Often the rash takes longer to go away than the muscle weakness.
Will I know if my child is having a flare (worsening) of JDM? How?
- Your child may feel weak, have a rash or feel generally unwell. Young children will often become very irritable when they are having a flare (worsening) of their JDM. If you are worried about the possibility of a flare (worsening), you should see your child’s specialist.

How will JDM affect my child in school?
- When the disease is active, your child may become more tired than usual at school and may find it difficult to concentrate.
- Muscle weakness can make it difficult to walk around school/college. Some children in the short-term need to have shorter days at school/college, but in time, this will increase to full days. We would recommend that your child participates in exercise, but when the disease is active, your child may need to miss PE (see exercise advice above). Your child’s physiotherapist will be able to guide you on this.

Can my child get extra help from school/college if needed?
- Schools/colleges can help to make it easier for your child to join in normally. When not feeling well, it may be advisable to focus on core subjects, reduce the workload, give time to catch up or rest, and provide extra time to get to classes.
- Your child’s medical team can help by talking to the teachers at school/college if any areas are proving difficult. With your permission your child’s medical team can write to teachers and provide more information about JDM.
- Lots of children/young people with JDM have gone on to university and/or have successful jobs.

Is there anything that children with JDM will not be able to do?
- Initially your child may struggle to continue with normal everyday activities. It may take a while for your child to get ‘back to normal’. With all of the medicines and therapies discussed, we would hope that over time your child would be able to lead a normal life carrying out all of the activities that they wish to.

Will my child’s puberty or growth be affected by JDM or by the treatments that they will be on?
- Growth and puberty can both be affected by active inflammation (pain, redness, swelling). The best way of improving growth is to control the disease.
- Steroids can also affect growth, but doctors will ensure that your child is kept on as low dose of steroids by mouth as possible. This is one of the reasons that other disease modifying medicines are used.
- When there is inflammation, puberty often occurs a little bit later than usual. If this happens, it actually means that your child will have more time to grow! Some children or young people may see a specialist in growth (an endocrinologist).

Will my child be able to have a family in the future?
- Your child should be able to have a healthy child in the future, despite having had JDM. Some people cannot have children for other reasons. Some medicines (such as cyclophosphamide) can affect fertility. However, this only occurs when large doses are given over a period of time and doctors will ensure that as low a dose as possible is given to your child to treat the disease. If the medicine is given before puberty, there is less risk to your child’s fertility.
- There are some medicines used to treat JDM that should not be taken whilst pregnant as they may damage an unborn child. It is therefore important that your child talks to their doctor if they want to become pregnant. Whilst they are taking these medicines, they should be using contraception to ensure that they do not become pregnant if having sexual intercourse.

What is in the future for my child?
- In some cases, children may have problems due to damage in their muscles/skin or calcinosis, but this is less likely if children are treated early in their disease. Children with a prolonged chronic course can be more at risk of complications.
- Your child should be able to lead a normal life, firstly taking medication and in time, without medicine. We would expect children to gain normal muscle strength and stamina over time and be able to carry out all activities, including sporting activities.

Can we meet other families that have children with JDM?
JDM is very rare. It only affects approximately four children in every million each year. However, your specialist will be treating other children with JDM. If you would like to meet them or talk to them, ask your specialist.