

Adult-Onset SMA-Diagnosis and Care

You can also read this guide on our website at smauk.org.uk/djya where you can follow all the links we give to further information.

Who this is for

This guide is for adults who:

- have had a recent diagnosis of an adult-onset form of SMA or
- are wondering if this might be what is causing symptoms they are experiencing.

It is designed to be used alongside medical advice. This should always come from a member of your medical team.

1. Trying to Get a Diagnosis

Getting a diagnosis of adult-onset SMA can take time. Symptoms often look like those of other neuromuscular conditions. Waiting for appointments and test results can be stressful and frustrating. If you're worried about your symptoms or have had tests but no further action, ask your GP for a referral to a consultant neurologist. As SMA is rare, many GPs may not have seen it before.

Possible tests are:

- an electromyogram (EMG). This shows if the nerve supply is diminished
- a muscle biopsy. This shows if there is any reduction in muscle cells
- an MRI (Magnetic Resonance Imaging) scan. This produces detailed images of the inside of the body

- a CT (Computerised Tomography) scan. This is another way of producing detailed images of the inside of the body
- a range of blood tests. These include a blood sample for DNA testing.

2. Different Forms of Adult-Onset SMA

Even with all these tests it's not always straightforward to say exactly what neuromuscular condition an adult has. A specific diagnosis of SMA Type 4 can be made following DNA testing.

The most common form of SMA is known as 5q SMA due to its genetic cause. 5q SMA includes SMA Type 4. If you have been diagnosed with SMA Type 4, you may also want to read:

- **What is 5q Spinal Muscular Atrophy?**
- **Symptoms and Effects of SMA – Type 4**
- **The Genetics of 5q SMA**

You can find these on the [About SMA page](#) > of our website.

The impact of adult-onset SMA differs widely from person to person. It can also change over time, regardless of the SMA type you have.

Our webpages about [Rarer forms of SMA](#) > tell you more about these adult-onset forms of SMA:

- **Distal SMA Type 5 (DSMA V)**
- **Spinal Bulbar Muscular Atrophy (SBMA) – Kennedy's Disease**

3. First Reactions to Your Diagnosis

Finally knowing your condition – and what it isn't – can bring mixed emotions for you and your family.

Some of the most common reactions people have include:

- Relief – you now know what your condition is.
- Shock
- Anxiety about the future
- Sadness and upset
- Anger or frustration

You may have all, some or none of these reactions. There is no 'right or wrong' way to feel. People can experience different emotions at different times. Whatever you're feeling, it's very understandable. Don't forget that as well as your partner, family and friends, there are other people you can turn to for support at any time. The section below on **Emotional Support** suggests sources of support.

There is a lot of information to take in. You will need to give yourself time to ask your clinical team all the questions you have, as many times as you need to.

4. Movement, Mobility and Exercise

It is rare for people with adult-onset SMA to be unable to walk. Whatever form of SMA you have, it is important to maintain as much movement and independence as you can. An individual exercise programme guided by a qualified practitioner can help you.

Unfortunately, being able to get the services you need varies greatly on where you live. Some areas have a neuromuscular centre (see the [Posture, Movement & Exercise](#) > page in our Living with SMA section). This is where specialist physiotherapists can set up a programme for you. If you don't have one near you, ask your GP to refer you to a neurological physiotherapist.

To set up your personal programme, a physiotherapist will need to understand your medical history. They will need to get a picture of your joint range, muscle power and what you are able to do. They may then need to see you at regular intervals to check how you are getting on.

An exercise programme would include:

• Stretching exercises

Your muscles and joints may become tight (contractures). The muscles and joints most affected are:

- heel (Achilles tendon)
- back of thigh (hamstrings)
- front of hip and thigh (hip flexors and quadriceps)
- outside of thigh (hip abductors)

You may also experience muscle tightness in your shoulders, arms and fingers. If your joint tightening is on one side, it can lead to poor posture or cause you discomfort. In time this may affect your ability with day-to-day tasks. Daily stretching can help this.

When stretching you may feel tension or pulling; but stretches shouldn't be painful. If they are, talk to your doctor or physiotherapist.

You might enjoy stretching in the bath, a swimming pool, or, if one is nearby, a hydrotherapy pool. Warm water can make muscles easier to stretch. Swimming is a good general exercise without risk of muscle damage or overdoing it. Check with your physio for safe ways to swim and to find local facilities. Most public pools offer changing areas for disabled people. If these don't work for you, your physiotherapist or occupational therapist (OT) may be able to advise.

- **Exercises for posture, standing, balance, muscle strength and control**

Good posture is important for the body and muscles to function at their best. This applies to sitting, standing and walking. You may experience muscle weakness in these postural muscles.

Posture exercises often involve working on the muscles in the abdomen. They focus on the deep abdominal muscles. These muscles sit under your "six-pack" muscles. This helps maintain good posture and balance. It is often called 'core stability'. Having good balance helps prevent falls. Exercise, such as yoga, Pilates and Tai chi can help you maintain standing balance, posture and muscle control. A physiotherapist will advise you about appropriate exercises.

Your physiotherapist may advise other strengthening exercises for any muscle groups that may be weak.

Standing is very important for many people with neuromuscular conditions, even those who can't walk on their own. Your physiotherapist might recommend a standing aid to assist.

Regular standing also helps normal functions like kidney drainage and reduces calcium loss in bones. It can also help to stretch the muscles in your legs such as your calf muscles.

- **Exercises to improve cardiovascular fitness, stamina and mental health**

It is very important to keep physically active to help keep your muscles as strong as possible. Being less active can have a negative impact on your ability to walk.

Physical activity also helps with mental health well-being and fatigue. You might want to try swimming or adaptive sports to stay physically active. Check with your doctor and physiotherapist about the right exercises for you. They can also tell you about local centres and organisations to try.

Our You Tube recording by three specialist physios may be helpful: [Adults & Exercise >](#)

Muscular Dystrophy UK have [Exercise advice for adults with muscle-wasting conditions >](#) You can request a copy by phoning 0800 652 6352 .

5. Managing Any Fatigue and Pain

People with adult-onset SMA sometimes report pain and muscle fatigue. This can be due to overusing some muscles to try and compensate for the weaker ones. If this happens to you, a physiotherapist may be able to help you manage better. Your GP might be able to prescribe suitable medication for pain relief.

It's important to sit and lie comfortably so that your muscles and joints can relax. It might help to use pillows to support certain muscles. Your physio can advise you how to do this.

A hot water bottle, heat pad, or a microwaveable heat bag can help relax muscles. A cold pack can also be used for pain relief.

Regular stretches and exercise may help with pain but please speak to your physiotherapist for advice on what is best for you.

Some people with adult-onset SMA may experience high levels of fatigue. This may be their most troublesome symptom. There are many different causes of fatigue. Some reasons why people with adult-onset SMA might be more fatigued than others are:

- Weaker muscles working harder to help you to sit, move and walk around
- Increased pain
- Problems with sleep
- Worrying about the future

- Stress
- Anxiety related to going out and about and the extra planning needed for this
e.g.
 - Where will I park?
 - Will I be able to use the toilet?
 - Will there be stairs?

You can better manage fatigue by pacing yourself. This prevents your body from becoming overly tired. Breaking demanding tasks into smaller chunks to allow you to rest in-between can be helpful. Planning your weekly schedule can also help to prevent you overdoing it. Make sure to factor periods of rest into your weekly routine.

If you work, consider asking about working from home or more flexible hours.

Although it may be difficult to imagine exercising when you are very tired, regular exercise can improve your stamina and endurance. Over time this will reduce fatigue. Doing small amounts of exercise throughout the day might be more manageable for people who are fatigued.

Regular exercise helps improve your physical ability and better understand your limits. Your physiotherapist and occupational therapist (OT) can advise you.

Muscular Dystrophy UK publish [Fatigue Management for people with neuromuscular conditions](#) > . Though not SMA specific, it may still be helpful. You can request a copy by phoning 0800 652 6352.

Some people with adult-onset SMA find meditation and mindfulness helps them manage pain and fatigue. There's a wide range of information on this on the internet and in libraries. Deep-breathing exercises can also be helpful, for example, in Tai Chi, Yoga or Pilates.

6. Diet

A healthy diet is important for everyone. If needed, your GP or consultant can refer you to a dietitian. They will provide you with advice and support on eating and nutrition.

Reduced mobility and lack of regular exercise can lead to weight gain. Extra weight increases the stress on muscles, bones and joints. This makes physical activity even more difficult. If this is happening to you, a dietitian can provide advice on a healthy diet to suit your needs.

Adult-onset SMA rarely causes difficulty with chewing and swallowing. This may though happen with Kennedy's Disease. Your medical team will provide you with advice and support with this if necessary.

7. Breathing

Adult-onset SMA doesn't usually cause problems with breathing. Talk to your clinical team if you have any shortness of breath, chest infections, early morning headaches or fatigue. They will discuss if you need any baseline lung function tests or a sleep study. Further assessments usually take place at your local ventilation clinic.

8. Treatment

The only form of adult-onset SMA that has a potential disease-modifying drug treatment is 5q SMA Type 4.

You can read more about this possibility on our page:

[Drug treatments for adults who have 5q SMA >](#)

So far there is no drug that treats the genetic cause of any other form of adult-onset SMA.

9. Medications for Other Health Issues

If you take any medications for health issues not related to your SMA, check with your consultant. They can advise you on how these may interact with your SMA.

10. Emotional Support

Receiving a diagnosis can bring some relief. However, living with adult-onset SMA affects both you and your family. It's crucial to have emotional support and time to talk. Some of these suggestions might be helpful:

- **Your Clinical Team**

You may be offered support from health and social care professionals. This could include:

- Your Neuromuscular Care Advisor (NMA)
- Your nurse or physiotherapist
- A counsellor or psychologist

Our information sheet: [Who's Who of Professionals >](#) tells you more about the people who may be involved in your care.

- **SMA UK's Support Team**

Our small, experienced [Community Support Team >](#) offers a UK-wide service for anyone affected by SMA. We are flexible in how we can support you. We can be in

contact by email, phone, text or virtual meetings (such as Microsoft Teams). If you would find it helpful to talk something through in person we can home visit. Though we do not give medical advice, we can discuss the support you and your family can access.

- **Family and Friends**

You may be worried about how your diagnosis and care will affect your family and friends. They will want to know how to support you, but it might be hard for them to know what to say or do. Sharing your feelings with them can help. There may also be practical things they can do to assist you (see more below).

- **Religious / Spiritual Support**

You may have your own religious or spiritual leader or community who can give you support.

- **The SMA Community**

Adult-onset SMA is very rare. People's diagnosis journey and the impact of their SMA may not be like yours. However, if you would like to talk with someone affected by adult-onset SMA, speak to our Community Support Team. They will see if they can arrange this.

- **Talking Therapies and Counselling**

Some people find it helpful to talk about their feelings and how they are managing day-to-day. You might have thoughts you haven't shared with your family, or friends. An independent, trained professional can be an option:

Free Talking Therapy Services:

- **England:**

The NHS offers Talking Therapies for anxiety and depression. You need to be registered with a GP to access them. You can refer yourself directly, or a GP can refer you. .

[Find out more >](#)

- **Scotland:**

NHS Scotland offers 'Living Life'. free phone support sessions using Cognitive Behavioural Therapy (CBT) based techniques. You can refer yourself for an assessment by phoning 0800 328 9655.

[Find out more >](#)

- **Wales:**

You can sign up for a free 12-week course of online therapy called 'SilverCloud'. This uses methods like Cognitive Behavioural Therapy (CBT).

[Find out more >](#)

Northern Ireland:

Referrals for any talking therapies must go through your GP.

[Find out more >](#)

Waiting times for an appointment with these services will vary and may be quite long.

- **Private counselling**

If you think counselling would be helpful and affordable , you could consider seeing a local private counsellor. These organisations can help you find one:

- **British Association for Counselling and Psychotherapy (BACP) >** – guidance on counselling and how to find a suitable counsellor. Phone: 01455 883 300.
- **Counselling Directory >** – online information about different types of counselling and a directory to search for qualified counsellors.

If you are not sure who to speak to or which is the right route for you, our [Community Support Team >](#) is here to talk through your options.

11. Practical and Financial Support

If you have been independent and always done things yourself, it can be emotionally difficult to let others take over. Help with personal care can be equally, if not more challenging to ask for. You may find it helpful to read our page on **Personal Life – Tab 1 Care and Relationships >**.

You may be eligible for financial support and benefits. This includes if you find you need and want external care and support from a Personal Assistant (PA). There is further information about this in our **Financial and PA Support pages >**.

For information and support or to find out more about an assessment:

- talk to our **Community Support Team >** and / or
- **contact your Local Authority >**.

12. Support and Resources

Support and advice can help you manage your symptoms and the effects of your condition. Your neurologist, GP, physiotherapist and OT will all support you.

SMA UK >

Phone: 01789 267 520

Email: office@smauk.org.uk

Our small, experienced **[Community Support Team >](#)** offers a UK-wide service for anyone affected by SMA. We are flexible in how we can support you and can be in contact by email, phone, text or virtual meetings (such as on Zoom or Microsoft Teams). We are also able to home visit if you would find it helpful to talk something through in person. Though we do not give medical advice, we can discuss with you the support you and your family can access.

The **[Living with SMA area of our website >](#)** gives useful information and ideas. It builds on knowledge and advice from the SMA Community and SMA UK's Support Services Team. It covers a whole host of topics. This includes equipment, homes, transport, leisure, holidays, financial, and emotional and social support.

We offer a number of ways for you to **[Connect with the SMA Community >](#)**.

We have a number of **[Grant Schemes >](#)** that may be useful.

You can keep up to date about events, new research developments and much more by **[signing up for our monthly E-news >](#)**.

[Muscular Dystrophy UK >](#)

Phone: 0800 652 6352

Email: info@muscular dystrophyuk.org

MDUK provide information, support and grants towards specialist equipment for people affected by a range of neuromuscular conditions.

Neuromuscular centres:

There are two neuromuscular centres in the UK. Both are charities. They offer physiotherapy, complementary therapies, support and advice to adults who have a neuromuscular condition. The services are free to the user, but you will need to be referred by your GP or consultant. Contact the centres for more information:

- **[The Neuromuscular Centre Winsford >](#)**

Phone: 01606 860 911

Neuromuscular Centre, Woodford Lane West, Winsford, Cheshire, CW7 4EH.

The centre covers mainly the North of England and North Wales.

- **[Muscular Dystrophy Support Centre >](#)**

Phone: 02476 100 770

Hereward College, Bramston Crescent, Coventry, West Midlands, CV4 9SW.

The centre covers the Midlands region.



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This publication, and its links, provides information. This is meant to support, not replace, clinical and professional care.

Find out more about [how we produce our information >](#).

If you have any feedback about this information, please do let us know at:
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