Medically unexplained symptoms

A guide for parents, carers, and families

Melbourne Children's
A world leader in child and adolescent health

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Foreword from Lived Experienced Advisors

Thank you for picking up this guide for families of children and young people with medically unexplained symptoms (MUS).

We want you to know that this guide has been developed with the help of Lived Experience Advisors (LEAs). We are people with lived and living experiences of MUS. Some of us have shared personal stories about our own journeys with MUS, and some of us have cared for a loved one. This guide has also been written with health professionals who have learnt from people's experiences with MUS.

Even though everyone's experience with MUS is unique, we understand how frustrating it can be to explain distressing symptoms, sometimes with no clear answers. Whether this is a starting place for you and your young person, or you have been on this journey for a while, we want you to know you're not alone.

By sharing our stories, we hope this guide will build compassion and help people and health practitioners to better understand MUS. We also hope it will strengthen empathic and kind treatment and support for young people.

Although the process may have brought back some memories for us, it's helped some of us grow. We know this guide will be a wonderful tool to help you and others understand that children and young people can experience real physical symptoms and pain without a medical cause.

We are proud of this guide, and it's important to us that it reaches those who need it. Without lived and living experience and input, things won't change for the better. So, thank you again and let's get started.

Cover artwork: "Abstract" by Alison Norman, Lived Experience Advisor.

Alison said, "My artwork showcases a variety of shapes, colours and textures - just as mental health experiences provide us with highs and lows. This represents the many intricacies and variables in each journey. I have painted with a positive and uplifting colour palette, and hope that viewers may see positivity too".

Key messages

- Living with any kind of symptom that impacts daily life is hard. It can be even harder when there doesn't seem to be a medical cause for why they are happening or a clear path for what to do about them.
- Trust your young person and listen to them when they tell you how they feel. It's important to recognise that what your young person is going through and their MUS are real and valid.
- We don't know what we don't know. Some health practitioners you and your young person meet with may not necessarily know about MUS and its care.
- MUS are common and there are people who understand. With the right care team and support system, young people can get help to live with and overcome their symptoms.
- It's okay to want to look for other opinions, but sometimes asking for too many tests can cause more stress for you and your young person.
- You're not alone on this journey. Remember to treat yourself with compassion, kindness, and take time for self-care for your own wellbeing.

Lived Experience Advisors involved in this guide:

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How to use this guide

This guide was created as a learning tool and a helping hand so that you, your loved ones, and your young person can better understand MUS. It provides a clear picture of what MUS are, how they can present, and how you can manage symptoms with your young person. This guide walks you through the processes of diagnosis and treatment, and the support options available. When it comes to MUS, knowledge is power!

Please consume this guide in any way you need. You can read in small chunks, read it more than once, or read along with someone if that helps.

It's a lot of information, but we've narrowed down the most important things you need to know while explaining some of the complicated medical jargon that comes with MUS.

Remember, it's important to stay curious and ask your young person's care team lots of questions. No question is a bad question.

There are four parts in this guide:

Part one: Understanding medically unexplained symptoms

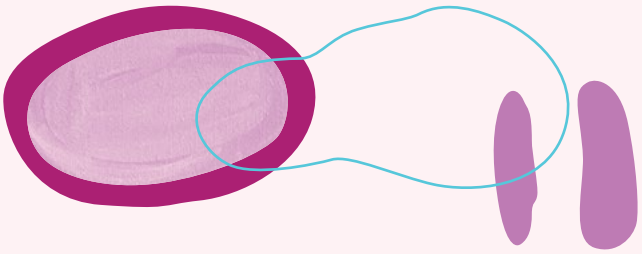
Part two: The mind-body connection and stress

Part three: Assessment and diagnosis

Part four: Treatment and recovery

We have also added some examples, key messages, and resources in each part, and a list of references at the end in case you and your young person want to follow up on more information.

Contents



Introduction

Your young person has real symptoms

When your young person is feeling sick or in pain, it's only natural to worry and want to protect and take care of them. After trying the usual ways to help reduce their symptoms and make them feel better, the next step may be to visit a health practitioner like a general practitioner (GP) or paediatrician. This is an important step towards getting help for them.

You and your young person may seek medical care because you believe the symptoms have a medical cause.[1-4] The hope is that they will find and treat this medical cause to help relieve your young person's symptoms. But if appropriate assessments and tests come back clear, they might say there's no medical cause for their symptoms. This can be confusing and understandably worrying, and you will likely have lots of questions.

You may feel some health practitioners doubt that your young person's symptoms are real, and you might even feel like your young person should just "soldier on". This can be frustrating if their very real symptoms continue to affect their wellbeing and everyday life.

Health practitioners may mention that your young person's medically unexplained symptoms (MUS) are caused by their emotions or stress. It can be difficult to have to consider that emotional or social problems are playing a part in your young person's symptoms. You might even blame yourself or feel like you missed something that your young person needed.

Accepting that there is no identifiable medical cause will improve your young person's chances of getting the right care and support, which will help their recovery.[5]

So please be encouraged by the fact that most MUS are temporary and can be treated.

This guide will help you make sense of your young person's symptoms, understand how and why they could be happening, learn about how MUS are treated, and feel confident to support your young person's recovery.

MUS affects people of all ages, but this guide focuses on what parents and carers may find helpful when supporting a young person with MUS. When we say "young person", we are talking about someone who is younger than 18 years old.

Some quick facts about MUS[6-7]

- MUS are common. Around 3 out of 10 young people who see a health practitioner for help with physical symptoms have MUS.
- MUS generally feel the same as symptoms caused by a medical illness and can occur in any part of the body.
- MUS can be worrying and might cause your young person to feel distressed or make it difficult for them to participate in their usual activities.
- In almost all cases, MUS are not caused on purpose and are not "made up" by young people.
- MUS is a hopeful diagnosis because it is treatable, and most young people will recover well with the right types of care (often by seeing a GP or paediatrician).
- Early diagnosis and treatment can help your young person feel less distressed and get back to the things they love doing sooner.
- Parents and carers can help young people a lot when it comes to MUS treatment and recovery.

Definitions

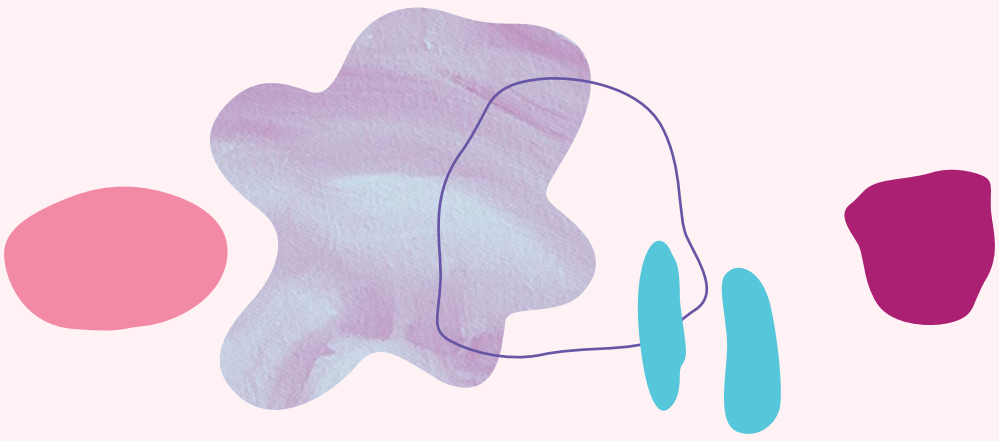
This guide explains some medical words that are helpful to know when talking about MUS with your young person and their health practitioners. **Table one** gives you definitions for some of the most common words that relate to the brain, nervous system, personality, and diagnosis.

We have provided definitions that make the most sense for understanding MUS, but it is important to know that some health practitioners may understand and use these words in different ways. A few of these words are likely to be new to most parents and carers, and it's okay to ask your young person's health practitioner to explain anything you're not familiar with or don't understand.

Table one: Common words used to describe MUS

Word	Definition
Medically unexplained symptoms (MUS)	When physical symptoms happen, but no medical cause can be found from assessments.
Symptom	A change that we might notice in the way our body is feeling or working. Symptoms can be a sign that we might have an illness (like when a runny nose might suggest hay fever or a cold).
Medical illness or cause	In this guide, a medical illness is caused by a physical infection or injury that directly affects the body and the way it functions. This illness can be a medical cause of other physical symptoms. Health practitioners can make a diagnosis of a medical illness by putting together information about symptoms, physical health checks or examinations (like listening to the heart or feeling the tummy), and interpreting information from tests or investigations (like blood or pathology tests).
Health practitioner	A generic term that describes a health professional who is trained to help with young people's physical or mental health care (like a GP, paediatrician, nurse, psychologist, physiotherapist or occupational therapist).
Care team	A team of health practitioners that work together to plan and oversee a young person's treatment and recovery. This team could include both physical and mental health practitioners.
Interoception	Our ability to sense and understand what's happening in our bodies, like when we are hungry, when we need to go to the toilet, or when we are in pain.
Somatising	When physical symptoms are caused by the body's response to strong emotions, stress, or other conditions like anxiety or depression.
Somatic symptoms	Physical symptoms that are caused by the process of somatising.

Word	Definition
Functional symptoms	MUS that don't have a known medical cause and impact a young person's ability to function (like movement, senses or cognition) and their daily activities (like attending school).
Nervous system	The system of nerves and cells that carry messages between the brain, spinal cord, and the rest of the body. It controls movements, sensations, and body functions.
Neurological	Refers to anything related to the nervous system, which includes the brain, spinal cord, and nerves. It describes things that affect how the body moves, feels, or thinks because of changes or problems in the nervous system.
Neurodivergence	Describes when people's brains develop or work differently from neurotypical brains. It can include conditions like autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), and dyslexia.
Trauma	Responses to exposure to a situation or event that is very distressing or frightening. The impact of trauma can cause changes in the way we feel, think, and the way our body responds (for example, we may feel frightened, have trouble thinking clearly, and feel shaky in our body).
MUS diagnoses	
Somatic symptoms and related disorders (SSRDs)	A group of diagnosed conditions that involve experiencing physical symptoms that may not have a medical cause.
Somatic symptom disorder (SSD)	A diagnosis where a young person has physical symptoms that last for six months or more. These symptoms are distressing and can cause disruptions in daily life and changes to routines.
Functional neurological disorder (FND)	A diagnosis where a young person's symptoms affect how their nervous system works, causing neurological symptoms like changes in senses or motor functions. FND is normally diagnosed when the neurological symptoms don't match any known neurological or medical conditions.



Part one
Understanding medically unexplained symptoms

Health practitioners can use many different words and terms to talk about what your young person is going through. Understandably, this can be confusing or hard to follow.

This part goes through some frequently asked questions and answers about medically unexplained symptoms (MUS), including some terms that you may have heard that describe the symptoms, and some reasons why your young person might be experiencing them.

What are medically unexplained symptoms?

Physical symptoms are changes we notice in the way our body feels or functions. They can happen as part of our usual day-to-day life, when we have a medical illness or injury, or when we experience strong emotions like stress or anxiety.[2]

Around 30 per cent of young people seen by health practitioners like GPs experience physical symptoms that don't have a clear medical cause or explanation.[6,7] These are known as medically unexplained symptoms (MUS), physical symptoms that are not caused by a medical illness.

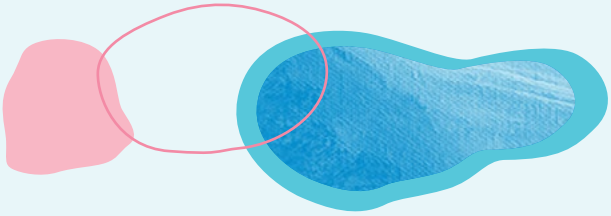
A health practitioner might talk to your young person about MUS if:

- they are confident after testing that there is not a medical cause for your young person's symptoms[8]
- your young person's symptoms are different from what might be expected for a medical illness (for example, their symptoms are a lot more severe, last longer, or have a different pattern)[9]

What causes medically unexplained symptoms?

Physical symptoms can be triggered by the body's response to emotions like stress or anxiety through a process called somatising.[2] MUS may be identified if the physical symptoms continue and no medical cause can be found. MUS are as real and impactful as symptoms caused by known medical illnesses.[9]

There are several reasons why your young person may be somatising. Sometimes, symptoms from a previous injury, infection, or illness may continue even after they've been treated and recovered.[9] Other times, symptoms can show up without an injury or illness. It's as if their body is trying to tell them something by turning emotions and stress into physical symptoms.[7]



EXAMPLE BOX 1

Mild somatising

Olivia's tummy ache

Olivia is a smart and curious young person who was looking forward to starting Grade 3 at her primary school. She likes writing but finds maths a bit hard. Over the school break, her parents got her a shiny new lunchbox, stationery, and exercise books.

On the first day of the term, Olivia felt unwell in the morning. Later that day, while working on a subtraction exercise in class, she started experiencing a tummy ache. Olivia had to visit the sickbay, and her mother was called to pick her up.

After some rest, Olivia felt better and was back at school the next day.

EXAMPLE BOX 2

Severe somatising

Daniel's headaches and vomiting

Daniel is a sporty teenager with dreams of making it to the Australian Football League. He was excited when he was selected for the senior school team, but he started to put a lot of pressure on himself to do well.

He began making mistakes during his football games and after one match, Daniel started experiencing strong headaches that made him feel sick and vomit.

These headaches became a daily struggle. He was so unwell that he stopped going to school all the time and quit playing football, missing the chance to join his team for the finals.

Worried about his intense pain, Daniel's parents took him to the hospital. Health practitioners ran tests to find the cause of his symptoms, but all the tests came back clear of any medical or neurological issues.

Daniel became isolated. He stopped hanging out with friends, playing or watching football, and had a hard time keeping up with his schoolwork.

Common medically unexplained symptoms

MUS can affect any system in your young person's body.[1] Here are some common MUS and the body systems they affect.

Table two: Common symptoms of MUS

Body system	Common symptoms
Neurological (brain, spinal cord, and nerves)	• headaches • dizziness • non-epileptic seizures • vision problems • numbness • tingling
Cardiovascular (heart, blood vessels, and blood)	• palpitations or noticing the heartbeat • racing heart • shortness of breath • fainting • chest pain

Body system	Common symptoms
Gastrointestinal (digestion)	• abdominal or stomach pain • bloating • nausea • vomiting • constipation • diarrhea
Musculoskeletal (bones, muscles, joints, tendons, ligaments, and cartilage)	• aches in all or part of the body • joint pain
Respiratory (lungs, breathing)	• breathing difficulties • shortness of breath
Ear, nose, and throat (hear, smell, swallow, and taste)	• sore throat • cough • runny nose • earache • ringing ears (tinnitus)
Genitourinary (bladder, kidneys, urethra, reproductive organs)	• urination difficulties • period pain • loss of periods
General health	• sleep problems • fatigue or tiredness

Understanding stigma

Society often views stress, emotional distress or mental health as less serious and valid than physical illnesses,[6,8-9] or people can feel uncomfortable talking about mental health issues. This stigma may affect how people view and interact with your young person with MUS, including family and friends.[6,7,9]

Because of stigma, people may:

- have limited knowledge and understanding of physical and mental health or MUS
- have negative beliefs about your young person and their symptoms
- accuse your young person of faking or exaggerating their symptoms
- keep their distance from your young person
- become angry or frustrated when your young person doesn't seem to improve

These attitudes can make your young person feel embarrassed or ashamed, especially when seeking care.[1] Because of this, your young person may be reluctant to talk about how stress affects them both emotionally and physically.

If this is the case, it is even more important to find healthcare practitioners who understand and will support your young person with MUS.

Key messages

- Living with MUS that impact daily life is challenging, especially without a medical cause for why they are happening.
- Somatising is a common reason for MUS, where emotions like stress or anxiety can lead to physical symptoms.
- Believe your young person. MUS are real physical experiences, regardless of whether a clear medical cause is found.
- Health practitioners who understand MUS can help your young person develop effective management strategies.
- Remember that these experiences are valid, you are not alone and treat yourself with kindness.

Links to more resources

Raising Children Network

- Helpful thinking: activity for children, teenagers and parents
- Understanding and managing emotions: children and teenagers

ReachOut

- Teaching your teens resilience

Kelly Mahler

- Interoception resources

Part two
The mind-body connection and stress

Many parts of health require the mind and body to talk to each other. This includes monitoring the body's wellbeing and needs as well as handling stress and emotions. Young people who experience MUS may not understand the mind-body connection or recognise their stress and physical symptoms.

For young people with somatising and MUS, stress can come from common sources, just like any other young person. But their stress may go unnoticed or hide in the background.

This part goes through the mind-body connection, stress, and some of the common factors in young people experiencing somatising and MUS.

The mind-body connection

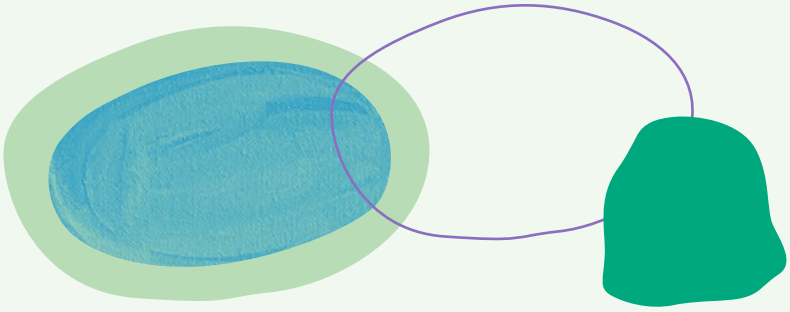
The way that your young person thinks, feels, and experiences the world is shaped by the connections between their brain and the rest of their body. Using complex messenger systems (**Figure one**), their brains are in constant communication with the rest of their body.

This information is shared via:

- signals from their **brain** to their **body** through:
  - their central nervous system, which sends electrical messages through the spine
  - neurotransmitters and hormones travelling through the bloodstream
- signals from their **body** to their **brain** through the five senses: vision, hearing, smell, taste, touch

This mind-body connection continuously monitors what's happening in your young person's environment and adjusts how the body functions in response.

There are many things that influence this mind-body connection, including personality, emotional styles, and abilities, as well as environmental factors like school and home.



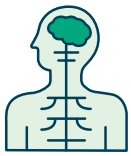
Major body systems

Hormones

Chemical messengers made by glands that travel through the bloodstream to send messages throughout the body.

Neurotransmitters

Chemicals in the body that carry messages from one nerve cell to the next.



Central nervous system

The body's main control centre, sending messages through the spine and nerves to and from the brain.

Autonomic nervous system

Controls body functions we're not aware of like heart rate, breathing, digestion, and the fight-flight-or-freeze response.

Endocrine system

Includes organs that produce and release hormones. Helps regulate metabolism, which is how the body turns food and drink into energy, releasing stress hormones into the bloodstream.

Immune system

Defends the body by fighting off germs that cause illness, like infections. It works with the other body systems to protect you.

Figure one: Major body systems

Understanding interoception

Interoception (pronounced *in-teh-roh-SEP-shun*) refers to your young person's ability to sense and understand signals from their body. This vital part of the mind-body connection involves nerve signals travelling from throughout the body to the spinal cord, then to parts of the brain with different functions.

Interoception includes:

- regulating basic body functions
- interpreting body signals as hunger, thirst, feeling hot or cold, or discomfort
- processing signals for pain and illness

Interoception is how your young person can tell if they need to eat, drink, rest, or if they're in pain or feeling unwell.[10,11]

Our parents and carers teach us how to understand and respond to body signals when we're babies, which shapes how we sense and react to sensations in childhood and beyond.[12] Our interoception skills get stronger as we grow.

Your young person's ability to notice and make sense of their physical symptoms through interoception may affect their MUS, and learning about interoception can help with their recovery.

Emotions, stress, and the mind-body connection

Emotions are part of the mind-body connection because all emotions have a physical part to them. For example, when we're scared or excited, our heart might beat faster, and we might breathe more quickly.[10,13]

Some young people find it easier than others to know when they're having strong emotions and to describe how they are feeling (like, "I'm feeling angry"). They can link their emotions to the physical sensations in their body (like, "my stomach feels sloshy because I'm feeling nervous").

Stress is a natural part of life, and some of it helps prepare us for action and provides motivation to achieve our goals.

The physical and emotional symptoms we get with stress are **real** symptoms.

Why stress may go unrecognised

While everyone experiences stress, your young person may not always recognise their stress or acknowledge it. Even if they deny feeling stressed, their bodies may be reacting naturally to stressful situations. For example, they may have a higher heart rate or blood pressure, changes in breathing patterns or tense muscles.

Your young person might not identify their stress because of their:

- difficulties understanding their emotional responses to their experiences
- difficulties understanding their body's signals of stress, needs or pain (interoception)
- confusion between physical symptoms caused by their emotions and medical illnesses
- concerns about the stigma associated with stress, mental health or MUS
- personality type, like perfectionist tendencies that can mask underlying stress
- already built in coping mechanisms
- unique responses to physical sensations

Sources of stress

When asking your young person, they will ideally tell you if they are feeling stressed at school or at home.[14,15] Finding out the sources of stress and dealing with those stressors can help your young person feel better.

Stress at school

School experiences and your young person's ability to cope can become a source of stress that contributes to their physical symptoms.[14-19]

School stressors can include:

- transitions and new responsibilities, like starting school or moving up to a new year
- struggling with a school subject or a teacher
- increased schoolwork and deadline pressure
- social conflicts and relationships with friends or peers
- bullying (in-person or online)
- missing school or falling behind
- unidentified or unsupported learning difficulties or neurodivergence
- not meeting their own or others' high expectations

EXAMPLE BOX 3

Addressing stress and feeling better

Lily's school stress

Lily had been feeling sick and nauseous for months. She started vomiting at school during the day. She visited her GP, but they couldn't figure out why she was feeling this way. She was put on medication to help with the nausea, but her symptoms didn't improve.

Lily cared a lot about doing well in school, but her grades weren't what she hoped for. She didn't want to let her parents down, so she didn't tell them or her GP about her school stress.

One day, Lily's dad had a talk with her. She opened up about how she was feeling and the worries she had about school. Together, they came up with a plan to handle her schoolwork and reduce her stress. They even learnt about deep breathing techniques to help her relax.

As Lily started to deal with her school stress, her nausea slowly went away. By facing her worries about school, she not only felt better but also found studying fun without those unpleasant physical symptoms.

Stress in the family

Family-related stress can cause physical symptoms or even make them worse.[4,14,15,17]

Family stressors can include:

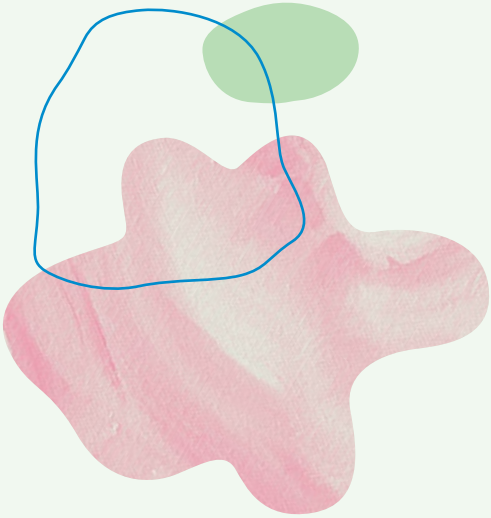
- major life events like illness, injury or death in the family
- parents or carers separating or going through a divorce
- family fights or conflicts
- parent or carer absence
- sibling relationships

Development-related stress

Childhood and adolescence are periods of exploration and self-development, learning new skills, attitudes, and values.[20] Your young person will go through lots of changes during these times, which can be stressful for them.

Developmental stressors can include:[4,17]

- participating in new activities
- developing their identity and sense of self
- physical development and body image
- questions about gender identity and sexuality
- social relationships and romantic interests
- early employment experiences
- transitioning toward becoming independent or growing up



The stress response system

Your young person's body will try to tell them when they're feeling stressed, threatened or unsafe as it communicates with their brain to keep their body systems in balance. **Figure one** explains what these body systems are.

Immediate response

When something is perceived as stressful, the body will respond in ways that immediately and temporarily disrupt the body's balance.[21,22] Their brain sends messages through their body to help them respond.[21]

For example, their autonomic nervous system (a body function that controls involuntary bodily functions like heart rate, digestion, and blood pressure without conscious thought) becomes more active, and stress hormones like adrenaline are released into the bloodstream,[23] initiating the "fight or flight" response.

This immediate stress response triggers things like:

- increased alertness
- racing heartbeat
- fast breathing
- tummy aches or discomfort
- tense muscles
- changes in digestion

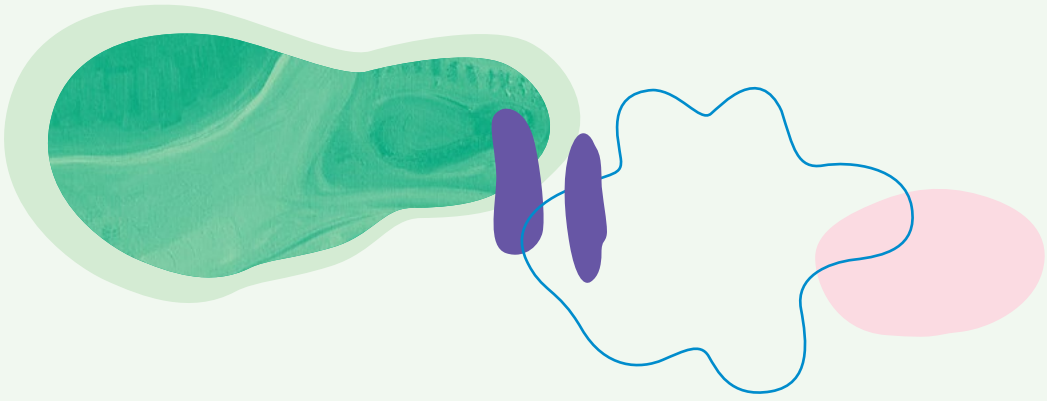
After something stressful, their body should gradually return to its balanced state. Hormone levels return to normal, heart rate and blood pressure go back to baseline, and their body's systems go back to their regular functions.[24]

Long-term effects of stress

If your young person's stress levels remain high, their body systems continue to be out of balance, and these temporary physical changes can develop into more long-term symptoms (**Figure two**).[9,22]

These long-term symptoms of stress can include:

- **neurological:** headaches, sensory changes, non-epileptic seizures
- **cardiovascular:** heart palpitations or noticing heartbeats, chest pain, fainting
- **respiratory:** breathing difficulties
- **endocrine:** higher levels of stress hormones
- **gastrointestinal:** stomach pain, nausea, changes in bowel habits
- **musculoskeletal:** pain, stiffness
- **dermatological:** skin reactions, rashes
- **general:** ongoing fatigue or tiredness, changes in sleep patterns,[9] disrupted learning, and increased wear and tear on the body



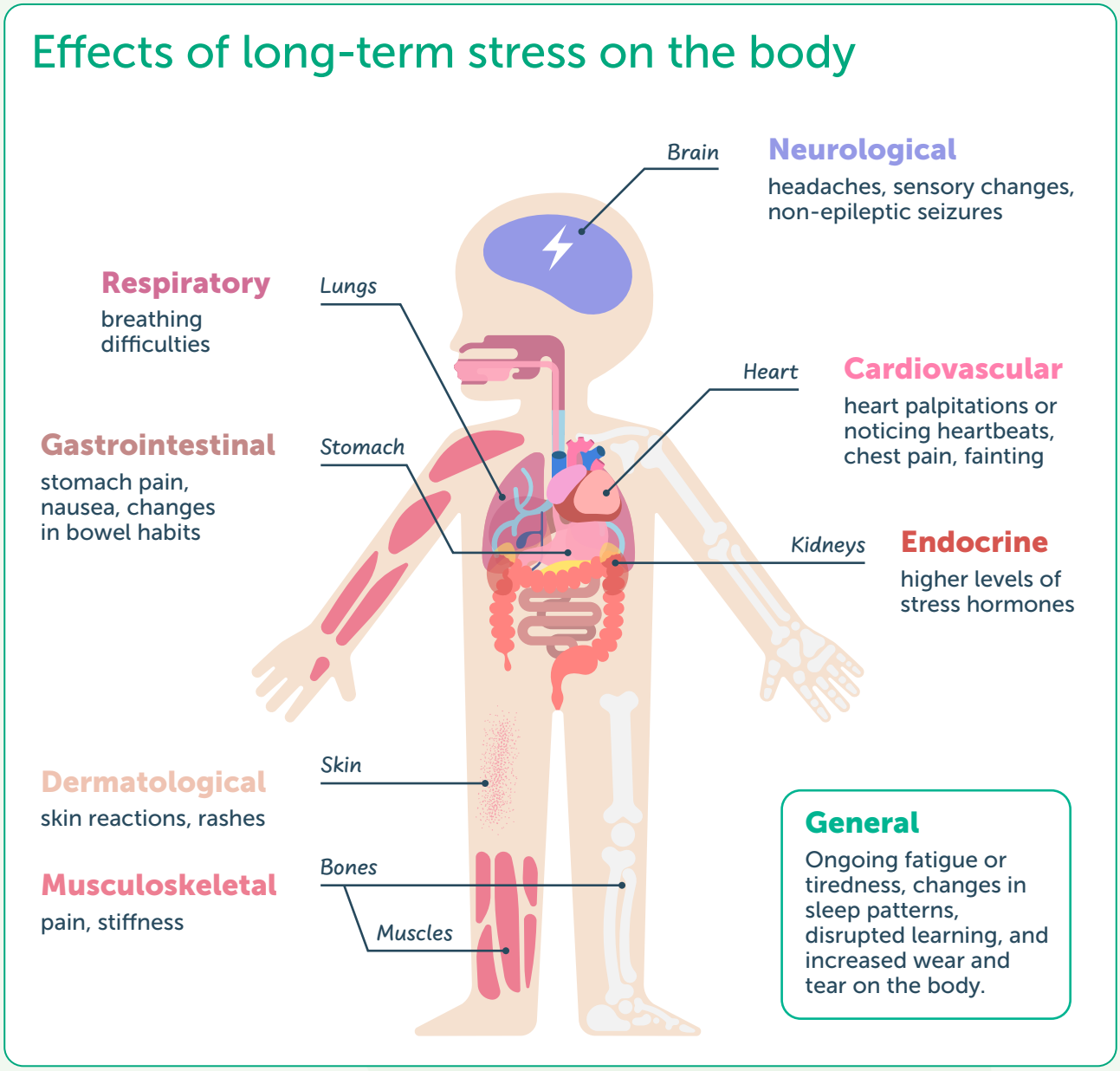


Figure two: Effects of long-term stress on the body

Common patterns of stress

There are ways your young person might handle their stress and emotions that can contribute to somatising and the development of MUS. This includes coping mechanisms like avoidance, dissociation, or attentional narrowing.

Avoidance

Avoidance is when young people cope with stress by trying to ignore negative memories, thoughts, or feelings. For young people with MUS, avoidance might be a way to escape from feeling tense, scared or nervous. It can give them short-term relief from these bad feelings.[25]

Over time, avoidance can cause the nervous system to become overactive.[4] When this happens, the natural stress response doesn't settle, which can worsen the physical symptoms.

EXAMPLE BOX 4

Avoidance

Bill's friendship problems

Bill is in Year 7 at high school and has been having problems with his friends. He's been feeling stressed and anxious about seeing them, which has caused him to have physical symptoms like headaches and stomachaches. To avoid these feelings and physical discomfort, Bill stopped regularly going to school.

Staying home from school helped Bill feel better because he wasn't thinking about his friendship problems. Over time though, avoidance made things worse for Bill. By not dealing with his friendship troubles and addressing the cause of his stress, Bill missed out on learning and keeping up with his schoolwork. He's started to worry about falling behind. His body's stress response has continued making his headaches and stomachaches worse.

Dissociation

Dissociation is when young people disconnect from what's going on around them. Your young person may dissociate or disconnect when they're really stressed, scared, or when something bad happens. They might even feel like they're not really in their own body.

Attentional narrowing

Attentional narrowing reduces your young person's focus to limit the amount of information they process when they feel overwhelmed.[26] In some cases, attentional narrowing can lead to physical symptoms, like dizziness, fainting, or non-epileptic seizures.[27-28]

It can also happen when a young person focuses too much on their physical symptoms, making them seem more harmful and dangerous. This can strengthen pathways in the brain linked to those symptoms, which can make the symptoms feel worse.

EXAMPLE BOX 5

Dissociation

Isla's bullying experience

When Isla was in primary school, she was bullied by some other kids in her class. Now that she's older, high school is okay for her, but when she finds herself in other situations where she feels threatened or humiliated, she can feel like she's disconnected from her surroundings.

When this happens, she says that she doesn't feel any physical pain or fear, and it's like her mind has temporarily separated from her body.

EXAMPLE BOX 6

Attentional narrowing

Riley's headaches

Riley has just started Year 12 and often feels sharp headaches that seem to come out of nowhere. When the pain starts, Riley finds it hard to think about anything else. Even if their friends are talking or there's something fun happening, Riley's mind is stuck on the discomfort. It's like the pain takes up all the space in their thoughts.

Sometimes, just noticing a small ache makes Riley worry that it's going to get worse, and the feeling grows stronger. When Riley feels pain, their mind zooms in on it and blocks out everything else. Because the focus is so strong, the pain feels even bigger and harder to ignore. Even small twinges get a lot of attention, making it seem like the problem is worse than it might be.

Key messages

- **The mind-body connection links emotions, behaviours, and physical responses.**
- **Interoception is the ability to sense, interpret, and process signals from inside the body, like feeling hungry, thirsty, tired or in pain.**
- **Your young person may:**
  - be very aware of their physical sensations
  - struggle to connect physical symptoms with emotions
  - minimise or deny that they are experiencing stress
  - need gentle encouragement to explore what's happening to them at school, home or in their personal development
- **You can help your young person understand that:**
  - stress is experienced through the connections between their mind and body
  - stress can be good, and help us do the things we want to do
  - ongoing unnecessary stress disrupts the natural balance of their body systems, leading to symptoms like MUS
  - emotions can be expressed as physical symptoms through somatising
  - their coping strategies may worsen their symptoms
- **Recovery begins when you and your young person acknowledge these non-medical causes and understand the mind-body connection's role in physical symptoms.**

Links to more resources

Raising Children's Network

- Stress and stress management: pre-teens and teenagers
- Social and emotional changes: pre-teens and teenagers
- Self-compassion: pre-teens and teenagers

ReachOut

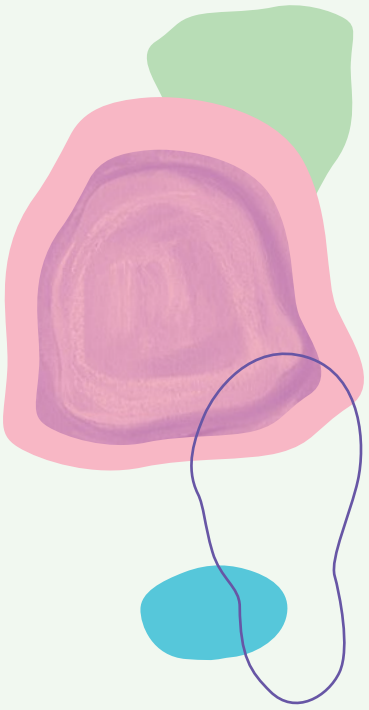
- Stress in teenagers
- Stress resources for young people: study, work and money
- Everyday issues resources for young people

Victorian Government

- Online tools and resources for learning difficulties

Articles

- The Guardian: Interoception: the hidden sense that shapes wellbeing
- Psychology Today: Is the mind-body connection real?
- Harvard Health Publishing: Understanding the stress response



Part three
Assessment and diagnosis

There isn't one single test or assessment to identify MUS, rather a range of tests that can rule out medical causes for your young person's physical symptoms. Health practitioners may suggest that your young person see a mental health practitioner to speak to them about their mental health and wellbeing, including any stresses.

This part focuses on the assessment and diagnosis of MUS, including the conditions your young person might potentially be diagnosed with, like somatic symptom and related disorders (SSRDs). It outlines the important role you play in working together with your young person's health practitioners when a diagnosis of MUS has been confirmed.

To help your young person's recovery, you need to come to accept the diagnosis of MUS and avoid seeking more medical assessments that aren't necessary. Remember, it's good to ask your young person's health practitioner all the questions you need to help understand what's happening.

What happens next?

As a concerned parent or carer, it's crucial that you feel confident that any medical causes for your young person's symptoms have been thoroughly investigated and identified.

Health practitioners will tell you which tests are needed to check for medical illnesses. Throughout this process, they should encourage and allow time for you and your young person to ask questions and raise any concerns (**Figure three**).

Figure three: Questions you can ask your young person's practitioner

Once all the required tests have been completed, health practitioners should explain the results clearly to you and your young person. If the tests have not found a medical cause for the symptoms, they should discuss the next steps with you and your young person.

At this point, or earlier, your young person may see a mental health practitioner, like a psychologist or psychiatrist, for assessment of their mental health and social wellbeing.[14-16] These assessments may identify conditions like anxiety or depression, as well as possible stresses that may be contributing to a diagnosable somatising condition. The mental health practitioner should talk to you and your young person about somatising, its causes, and the different treatment options available.

They should also explain if and why more tests may not be helpful. It's important to know that tests and procedures can be both physically and emotionally painful, and in some cases, they might even make your young person's symptoms worse.

EXAMPLE BOX 7

Ongoing tests

Miles' seizures

Miles is an 18-year-old who started having seizures when he was 16. Miles and his mother, Simone, visited health practitioners to find the cause of these seizures. When the practitioners did many tests to uncover the reasons behind Miles' seizures, something unexpected happened. Miles' seizures got worse and became more frequent.

Eventually, the specialists told Miles and Simone that the test results showed the seizures were non-epileptic, meaning they were not caused by abnormal brain activity. They were also told that the seizures would respond to non-medical treatment. Because of this, they decided to stop searching for brain-related causes of the seizures.

After tests were completed and treatments began, a major change took place. Miles' seizures started to improve, and over time, they eventually stopped altogether.

Tests and assessments

History

Recording your young person's medical and symptom history is an important part of assessing for MUS.

This information helps your young person's health practitioners to:

- understand the types of physical symptoms your young person is experiencing and their impact
- learn about what is going on in your young person's life that might be contributing to how they are feeling
- decide what other information they might need to make a diagnosis

Your young person's health practitioner might ask questions about:

- what the symptoms are like (like where in the body, or when they happen)
- how the symptoms are affecting your young person's activities (like going to school or doing fun things)
- any medical conditions your young person might have, and if they are taking medications
- any big changes or things that might be causing stress for your young person
- if your young person or anyone else in your family has been diagnosed with MUS or other serious health conditions
- the story of your young person's life (for example, what things were like before they were born or when they were very little)

Physical examination

Your young person will need a physical health check or a physical examination, depending on their symptoms. Their health practitioner should explain what examinations they need to do and why, ask you and your young person's permission before they start, and check in with your young person as they go.

Multidisciplinary assessment

Sometimes, your young person's health practitioner may suggest including another clinician to be a part of the care team and assessment. For example, they may recommend that your young person see a physiotherapist, occupational therapist or a mental health practitioner. They will be able to identify any problems with movement, function, and any symptoms caused by common mental health conditions like anxiety and depression.

Tests

Testing is not a one-size-fits-all for MUS. There are a variety of tests your young person's health practitioner could perform to make sure your young person doesn't need treatment for a medical illness.

The health practitioner will explain if:

- the test will add important new information
- the test will cause pain or discomfort for your young person, or make things worse
- there are other ways to get the same or similar information (for example, a less painful test, checking how the symptoms change over time, or using physical examination instead)

What is the diagnosis?

Like many other conditions, health practitioners diagnose MUS by bringing together information by talking to you and your young person, examining your young person, doing tests like scans or blood tests, and a mental health assessment.

It can be hard to hear the health practitioner confirm that your young person is experiencing MUS. But giving a name to the physical symptoms can be an important part of supporting your young person to get the right kind of care to help them recover as quickly as possible.

You might be told about **Somatic symptom and related disorders (SSRDs)**. These are a group of mental health conditions that involve physical symptoms which cause significant distress or disruption in daily life, along with a lot of thoughts, feelings, and behaviours about those symptoms.

SSRDs include two main types of diagnoses: **somatic symptom disorder (SSD)** and **functional neurological disorder (FND)**.

Somatic symptom disorder (SSD)

Your young person's health practitioners might consider a diagnosis of SSD if they have been experiencing somatic symptoms for at least six months and the symptoms are distressing or interrupting their daily life.

Young people with SSD may:

- constantly worry about their symptoms
- experience intense anxiety about their health
- spend a lot of time and effort managing their symptoms, like researching a lot or seeking multiple medical opinions

EXAMPLE BOX 8

Somatic symptom disorder (SSD)

Jake's ongoing and severe stomach pain

Jake is a 14-year-old boy who lives with his parents and older sister. For over six months, he has had severe stomach pain, which has led to multiple visits to the Emergency Department. In the past, Jake injured his shoulder in a school accident, and his recovery took quite a while.

During one hospital stay, health practitioners did tests to look for medical reasons for Jake's stomach pain. At the same time, the mental health team asked him questions about his background, mental health, and social life. During the mental health assessment, Jake said he wasn't stressed about anything other than his pain.

But his parents pointed out that he was missing a lot of school, even though he didn't believe he had any problems at school. The school said Jake was having trouble keeping up and wasn't performing as well as his older sister.

Jake's health practitioners couldn't find a medical cause for his stomach pain, so after consulting with a psychologist and a psychiatrist, his care team diagnosed Jake with SSD because his symptoms were causing him significant distress. It turned out the hidden source of stress that was triggering his stomach pain was related to worries about his schoolwork (somatising).

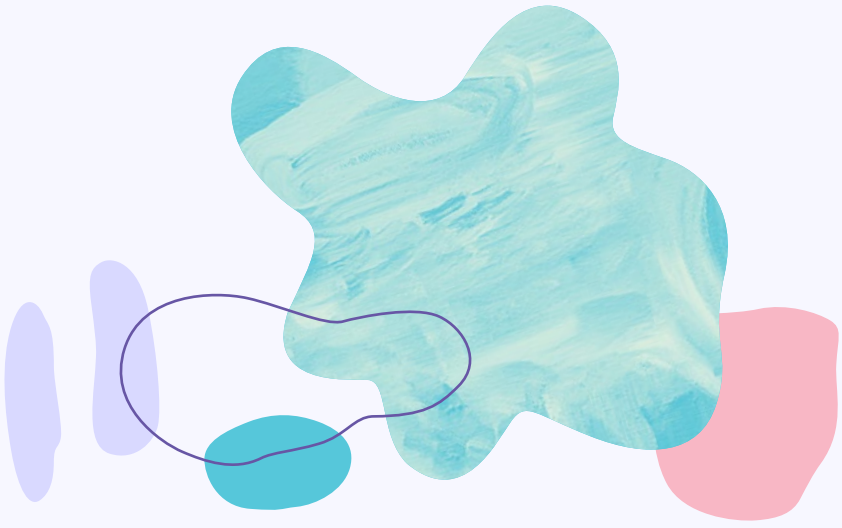
Functional neurological disorder (FND)

Your young person might be diagnosed with FND (sometimes called conversion disorder) if they are experiencing neurological symptoms that affect their senses or physical abilities.

In FND, these symptoms can cause your young person to feel distressed and get in the way of their daily life and normal activities.

Common FND symptoms can include:

- weakness or paralysis (unable to move)
- unusual movements (tremors or stiffness)
- changes in walking ability
- changes in vision or hearing (like reduced clarity, or vision loss)
- speech differences (like volume, clarity, or slurred words)
- skin numbness
- feeling tightening of the throat
- non-epileptic seizures



EXAMPLE BOX 9

Functional neurological disorder (FND)

Anna's inability to walk

Anna is a Grade 6 student. While playing sports, she collapsed and couldn't walk. Over the next week, she lost the strength in her arms and legs and had numbness throughout her body. Her family was really concerned and took her to the local hospital, where they ran tests. All these tests came back normal, with no signs of a medical or neurological condition.

Because of her symptoms, Anna was sent to another hospital, where she had to use a wheelchair to get around. During her hospital stay, she underwent both medical and mental health assessments to get to the bottom of her symptoms. The medical tests showed that her physical symptoms weren't because of any known illness, and the physical examination by a neurologist suggested a diagnosis of FND.

In her mental health assessment, Anna said she was struggling at school and was being teased by her classmates, who called her dumb. The psychologists found that Anna had learning difficulties, which made it hard for her to keep up with her schoolwork. School caused Anna lots of stress and worry.

A team of medical practitioners, psychologists, and psychiatrists who were managing Anna's symptoms met with her and her family. They diagnosed Anna with FND. They made this diagnosis because her symptoms didn't match any medical conditions, and they got worse by somatising because of the background stress she was having about school.

Getting a second opinion

If you and your young person are concerned that a medical illness may have been missed, seeking a second opinion from another health practitioner can be worthwhile. Seeing a different practitioner at the same hospital or medical clinic is usually a good option.

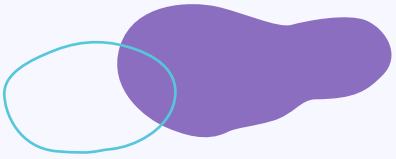
Try to avoid seeing lots of different health practitioners or specialists without them working together and communicating. When health practitioners don't share information, it can lead to different diagnoses, confusion, mixed messages, or treatments that don't work well together. This can make things worse for your young person.[4]

Accepting the diagnosis

Some parents and carers find it hard to accept their young person's diagnosis of MUS or a somatising disorder. For some, talking about mind-body connections, emotions, stress and mental health can feel unfamiliar, and others might worry that a serious medical illness has been missed.

Research shows that your young person is more likely to recover when you accept this non-medical cause.[6] It is important to avoid tests and treatments that aren't needed because they can cause distress and recovery might take longer.

You should talk to your young person's health practitioner if you are having these concerns or having difficulty accepting your young person's diagnosis.



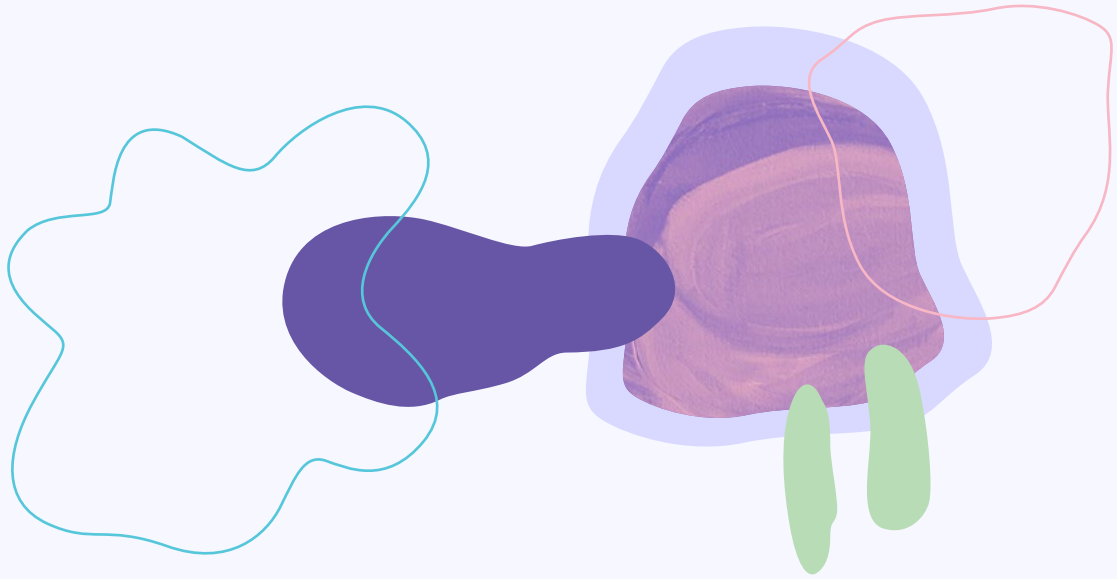
Key messages

- **The assessment process is an important part of making an MUS diagnosis and should include physical and mental health practitioners.**
- **While tests are necessary for investigating medical causes, too many tests for the same symptoms can be harmful, distressing, and may delay your young person's recovery.**
- **Open communication with health practitioners is important. Ask all the questions you need.**
- **An SSRD diagnosis may be appropriate when your young person's physical symptoms don't have a known medical cause but are significantly impacting their daily life.**
- **Your young person's recovery will improve if you can accept their MUS diagnosis after a comprehensive assessment.**
- **With the right treatment, your young person can recover and return to normal functioning and quality of life.**

Links to more resources

FND resources

- FND Australia: patient resources
- FND Australia: directory of health professionals with interest and expertise in FND
- FND Guide: Functional neurological disorder (FND)
- Clock Yourself: an app that combines cognitive and physical challenges into a brain game ($4.99)



Part four
Treatment and recovery

A young person with MUS will have physical symptoms, so, understandably, parents and carers will seek medical care for their young person. Even though MUS don't have a medical cause, a range of treatments are available when these symptoms cause distress or start to disrupt everyday activities.

This part covers functional rehabilitation and some of the physical and mental health treatments and supports that will help your young person and you manage their symptoms, reduce the impact on their daily life, and recover from MUS. It also goes through some of the parent, carer, and family wellbeing supports to help you and your loved ones.

Medically unexplained symptoms are treatable

Most young people with MUS get better with the right mix of treatments and support.[29-33]

Every young person is different, and your young person's treatment plan will need to meet their individual physical and mental health needs.

The main goals of treatment for your young person are to:

- help their MUS to get better with time
- improve their wellbeing[30]
- help them return to their normal activities (like school and reconnecting with friends)

Waiting for your young person's symptoms to get better before returning to their normal activities doesn't tend to work. It can actually make it harder for them to get back to the things they love. It's normal for your young person to still be experiencing symptoms during treatment, which can understandably make you both worry. But it's important to encourage and support them throughout this process.

What is a care team?

Your young person will likely continue to see their usual health practitioners, like a GP or paediatrician, for treatment. They might also ask other health practitioners to see your young person, as part of a care team. This team of different practitioners will look after the physical and mental health treatment plans, monitor if they're working, and adjust if needed.

This care team may include:

- **mental health practitioners** like psychologists or psychiatrists who provide mental health care
- **social workers** and support staff who help your young person manage daily challenges and improve their wellbeing
- **school-based support workers** who can help at school if MUS are affecting your young person's attendance or learning (like finding ways to reconnect with friends, organising rest breaks, making sure the learning spaces are accessible for your young person, and their learning is supported)
- other health professionals like **occupational therapists or physiotherapists** if your young person's symptoms are affecting their daily function and how their body moves

Functional rehabilitation

Functional rehabilitation involves care that focuses on improving your young person's symptoms by supporting them to get back to their normal daily activities. Your young person's health practitioners will work with you both to design a functional rehabilitation program that meets their needs.

To determine your young person's functional rehabilitation program, their health practitioner will:

- set goals that are important to your young person (like getting back to school or hanging out with friends)
- bring together a range of treatments that support the physical and mental health and wellbeing of your young person
- regularly check in with your young person to support their progress

Functional rehabilitation program activities could include:

- looking at things in your young person's environment (like stress at school or home) that can make things worse
- using mental health strategies to lower your young person's stress or distress (sometimes with a mental health practitioner)
- working with your young person's school to find ways to help them attend even when they have symptoms

For your young person to have a successful rehabilitation and recovery, you need to understand and accept:

- there is no medical illness causing their symptoms
- the importance of them continuing their normal daily, social, and school activities
- the safety of encouraging their physical activity despite discomfort

EXAMPLE BOX 10

Functional rehabilitation

Lucas's hospital visit

Lucas is 11 years old and lives with his parents and younger brother. He went to the hospital with a three-month history of tiredness, headaches, nausea, and weight loss after a viral tummy infection. When he was admitted, Lucas couldn't walk and was in a wheelchair because of weakness. He also couldn't eat because of nausea. His tests, including neurological and gastroenterological exams, were all normal.

Lucas is in Grade 5 at school and sometimes avoids doing activities unless he knows he will be good at them. He can be controlling and stubborn when he feels anxious. His family seems to be divided. Lucas normally sides with his mother, and Lucas' father sides with his younger brother.

When admitted to hospital, Lucas needed a nasogastric (nose to stomach) tube for feeding but he still refused food. He complained about weakness even though his physical tests were normal. His symptoms seemed to get worse when he was with his mother. The care team thought there might be some psychosocial (psychological and social) stresses and referred Lucas to get a mental health assessment. This assessment found Lucas had an underlying anxiety disorder, which got worse when he felt the tension in his family.

Functional rehabilitation for Lucas

Lucas's care team put together a functional rehabilitation program for him. This program focused on his physical symptoms and his psychosocial stresses to support his recovery. Lucas had regular review meetings with the whole team to check his progress, and he gradually got better.

Lucas's discharge

When Lucas went home from the hospital, ongoing mental health support was set up to help him go back to school. His school helped coordinate this, and they worked with both Lucas and his mother to help their relationship and encourage him to get back to his normal activities. Lucas's parents were offered a referral for family therapy to support their wellbeing.

Common treatments within functional rehabilitation programs

Your young person's health practitioner (or care team) might talk to you about one or more of these common treatments for MUS.

Psychological treatments

Mindfulness

Mindfulness is a technique that teaches your young person to stay in the present moment.[34] It can help your young person to:

- develop awareness and control of their thoughts
- be aware of what's happening in the moment and accept it in a non-judgemental way
- focus on one thing at a time
- notice and understand their sensations and emotions rather than reacting to them

Family therapy

Family therapy is a type of counselling that works with the whole family to help your young person with MUS by:

- dealing with challenges and conflict in the family
- building the whole family's understanding of MUS and what causes them
- helping the family feel balanced and supported
- looking after everyone's wellbeing
- finding ways to cope and work together as a family unit

Cognitive behaviour therapy (CBT)

CBT is a type of psychological treatment that looks at how your young person's thoughts and feelings can affect their actions.[29-30,34]

CBT can improve how your young person's nervous system responds and helps reduce their symptoms by:[29]

- changing their thoughts or beliefs that may make their MUS worse
- dealing with their experiences with MUS, like how they think about and react to their symptoms
- building useful coping strategies
- setting and working towards small and realistic goals

Family CBT involves parents, carers, and family members. It helps everyone work together to support your young person's recovery and return to normal functioning.[31,35]

Eye movement desensitisation and reprocessing (EMDR)

Some young people with MUS may have gone through stressful or traumatic events before their symptoms started.[16,17] EMDR is a treatment that can help heal this emotional distress.[32] During EMDR, your young person will be guided to move their eyes in certain ways while thinking about their upsetting memories.

EMDR can help your young person by:

- bringing traumatic memories into the healing process
- improving FND symptoms and mood
- assisting with their overall wellbeing and functioning

Your young person may need a referral from a GP or a psychiatrist to start EMDR.

Physical treatments

Rehabilitation

Your young person with MUS may have lost some physical strength and fitness over time. Working with physiotherapists, occupational therapists, and other rehabilitation practitioners can help them move their bodies and function again. These therapies can also help boost their energy levels, fitness, and overall wellbeing.[33,35]

Medication

The health practitioners treating your young person may suggest medications to help with the MUS. They can help with reducing physical symptoms and discomfort, as well as treat sleep problems, or conditions like anxiety and depression, which can make symptoms worse.[34]

However, treatments that only focus on symptoms (like heavy pain medications) are usually not helpful for treating MUS and can sometimes make things worse. This is because MUS are not caused by a medical condition, so treatments for physical symptoms often don't work very well.

What does recovery look like?

Recovery looks different for everyone, and it's important to know that it may take a while for you to notice any improvements. Your young person is not expected to get back to everything all at once. Your support throughout the whole process is key.

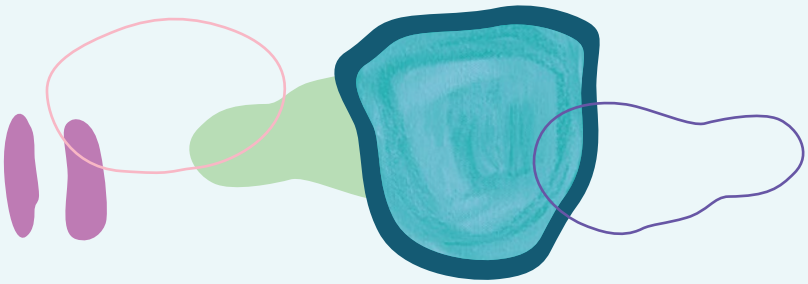
While your young person is receiving treatment, regular reviews with their care team are needed. Please remember that their symptoms may decrease or even disappear, but they could also come back with future stresses or big life changes. Learning ways to effectively manage symptoms will help your young person to reduce or prevent their MUS in the future.

Supporting your young person

Getting back to normal activities despite having symptoms takes some bravery. You can support your young person to feel safe enough to take this step by listening, supporting them to talk to their health practitioners, acknowledging how hard they are working, and celebrating their wins.

You can help your young person by:

- acknowledging their symptoms are real
- encouraging them to talk about their stress and express their emotions
- explaining the connection between their emotions and physical symptoms
- supporting them to gradually work towards their functional goals
- promoting healthy activities and mindfulness practices
- working on consistent routines for sleep, exercise, nutrition, and diet
- supporting and encouraging them to attend school and social activities, like hanging out with friends



Support for family members

MUS can affect your family and can be stressful for everyone.

Some of the ways you and your family can look after your wellbeing include:

- being compassionate and kind to yourself
- using breathing exercises and physical relaxation techniques
- doing regular mindfulness and reflection activities like meditation
- staying positive and hopeful
- seeking support or talking to other parents, carers or support groups
- connecting with healthcare resources and information

Key messages

- **MUS are treatable. For your young person to have successful treatment and recovery, they need an individual plan for their unique needs and a combination of healthcare practitioners and supports.**
- **It's normal for your young person to still experience symptoms after they start to get back to fun and important activities as part of their functional rehabilitation, treatment, and recovery.**
- **Make sure to monitor your young person's progress and ask about adjustments with their care team if needed.**
- **Your support alongside treatments can reduce your young person's stress and improve their wellbeing.**
- **Recovery can sometimes be gradual, but your young person should show significant signs of improvement over time.**
- **Building strategies to manage symptoms can help protect your young person from future stress.**
- **There are supports available for you and your family during this challenging time. Make sure to explore the resources we've provided or speak to your healthcare practitioners.**

Links to more resources

ReachOut

- Words you need to know – Mental health (for parents and carers)
- Professional help
- What to do after a diagnosis of chronic illness
- How to cope when things feel out of your control
- What are sleep disorders?
- What are your healthcare rights?

Raising Children's Network

- Mental health assessment for pre-teens and teenagers: a guide
- Mental health therapies and treatment plans for pre-teens and teenagers
- Self-compassion for parents
- Breathing exercises: relaxation activity for children, teenagers and parents
- Muscle relaxation activity for children, teenagers and parents
- Health Reference: Social worker

FND resources

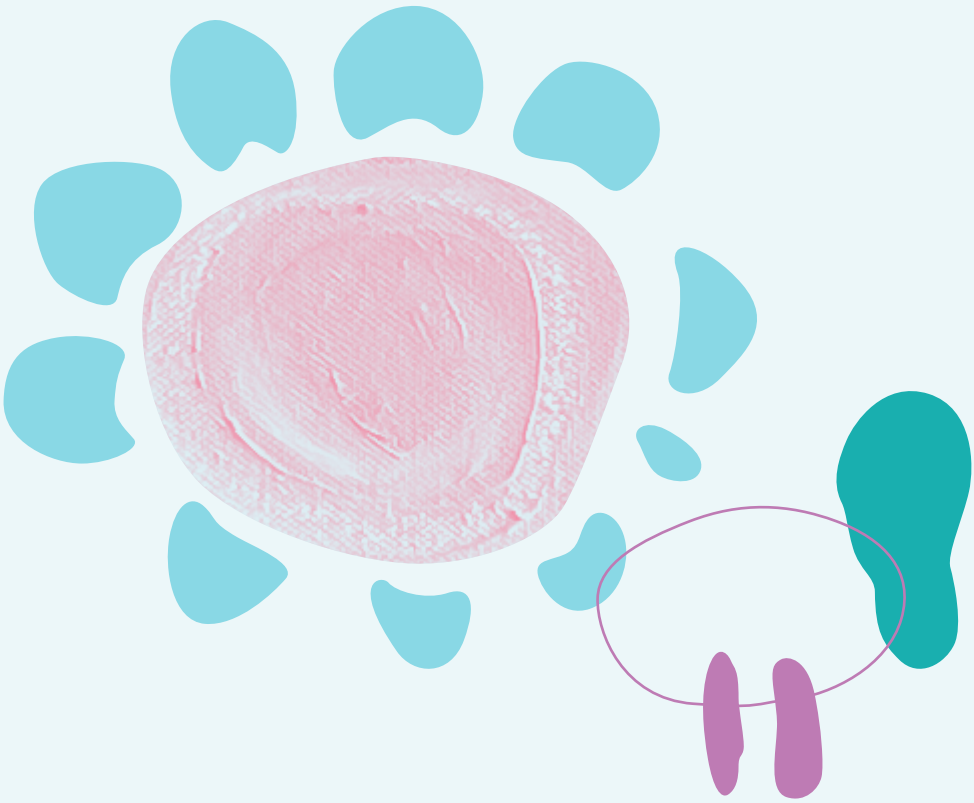
- FND Australia: Physiotherapy factsheet
- FND Australia: Psychology factsheet
- FND Guide: Treatment

Australian Psychological Society

- Demystifying EMDR

Headspace

- What are mental health difficulties and when to seek help
- Explore mental health and wellbeing topics for young people



Summary

Managing the uncertainties of MUS and SSRDs can be very hard, but remember, you're not alone on this journey.

With the right support from health practitioners, your young person can learn to manage their symptoms, improve their overall wellbeing, and get back to the things they love to do.

By focusing on both physical and mental health and identifying the stresses that may exist, you can help them develop healthy coping strategies and regain a sense of control over their lives.

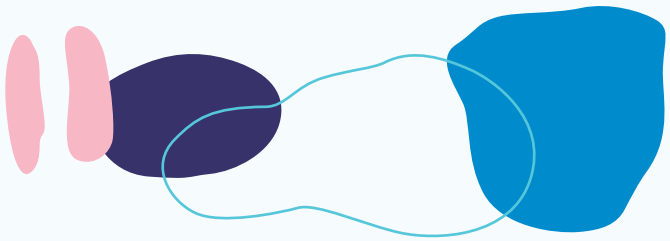
You play a key role in getting them back on track, and together with health practitioners, you and your young person can work towards a brighter, healthier future.

Final message from our LEAs

We hope this guide is a helpful friend to you, offering guidance and support as you navigate the journey of MUS with your loved one.

Just by being here and reading this guide, you've taken a significant step toward healing and support. Showing patience, unconditional love, and acceptance is one of the most powerful things you can do.

Remember, this guide isn't going anywhere; you can revisit it anytime you need reassurance or tips. It's okay to reach out for more help or information. It's a sign of strength.



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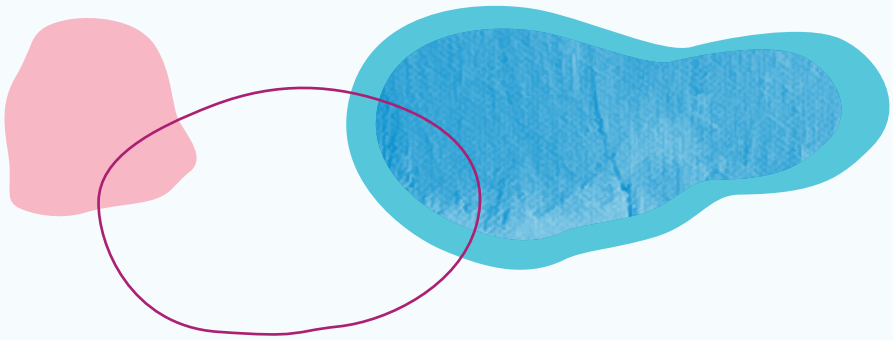

Medically unexplained symptoms

A guide for parents, carers, and families

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