







About this guide

Welcome to Going to the General Practitioner (GP) about your mental health – a guide for Autistic women.

This guide was developed using research by Brown, C.M., Ransley, F.R., Sinclair, J.L. & Stokes, M.A. (2019). My autism my mental health.

Unpublished. Data were collected via a survey of 236 Australian women aged between 18 and 71 years old (110 Autistic women and 126 non-Autistic women). The data were statistically analysed to test for differences in mental health needs between Autistic women and non-Autistic women.

The research shows that:

- Autistic women have greater mental health needs than non-Autistic women. In the study fewer Autistic women showed normal levels of mental health symptoms than non-Autistic women. On mental health questionnaires more Autistic women scored within the 'high eating disorder risk' category, 6% of Autistic women scored within the 'normal' range for anxiety and 11% scored within the 'normal' range for depression.
- mental health screening tools are not user-friendly for Autistic women because the language used is hard to understand and may be misunderstood if taken literally.
- there's a need for specialised mental health screening tools to be developed for Autistic women.

Amaze also consulted with Autistic women about their experiences of identifying mental health concerns and seeing a GP about their mental health concerns. We did a thematic analysis of their responses.

We found that:

- Autistic women face specific challenges in identifying that they have a mental health concern.
- Autistic women also face specific challenges in seeking support from their GP.
- Autistic women use a range of strategies to identify mental health concerns and to seek support from their GP.

Thank you to all of the women who took part in the research survey and the workshop for their valuable input.

Amaze would like to thank the Advisory Committee: Pia Bradshaw, Carol O'Dwyer, Prue Stevenson, Associate Professor Mark Stokes and Vanessa Thomas and our expert reviewers: Stephanie Crawford, Kathy Isaacs, Sally Sant, Associate Professor Mark Stokes and Vanessa Thomas.

Amaze thanks the William Henry & Vera Ellen Houston Memorial Trust Fund managed by Equity Trustees for their support in funding this project.

This guide was developed by the team at Amaze: Elena Ashley, Claire Brown, Claire Holden, Fiona Ransley, Joanne Sinclair, Rory Sinclair and Lived Experience Consultant Prue Stevenson (watercolour illustrations).

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How to use the guide

This guide has seven sections. You can use any of the sections which meet your needs. You don't have to read the whole guide for it to make sense. You can download individual pdf files from the sections you'd like to use or download a pdf copy of the whole guide.

The sections are:

- About this guide
- Do I need to see a GP about my mental health?
- Before the appointment
- Appointment day
- After the appointment
- Links to more resources, and
- References.

This guide is designed to help Autistic women to talk to a GP and refers to Medicare and the Australian health system. If you're outside Australia and are seeking support for your mental health contact your local autism organisation.

This guide is designed to help Autistic women talk to a GP about mental health support. This guide doesn't cover the National Disability Insurance Scheme.

Contact the Amaze Autism Connect advisors for more information about autism, or to talk about your individual situation:

Phone: 1300 308 699

Email: info@autismconnect.org.au

Website and webchat: www.amaze.org.au

This service is available from 8am to 7pm, Monday to Friday

(excluding public holidays)

Anyone who has concerns about their mental health and needs support with communication, memory and/or organisational skills may also find the guide useful.

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If you need urgent help or life is in danger dial 000.

This isn't a crisis guide. If you're in crisis please contact,

Crisis Support

■ Lifeline — 13 11 14

National free crisis counselling service. Available 24 hours a day.

Beyond Blue — 1300 224 636

National free mental health counselling service. Available 24 hours a day.

• <u>1800 RESPECT</u> — **1800 737 732**

National sexual assault, domestic and family violence counselling service. Available 24 hours a day.

Parentline (ACT only) — (02) 6287 3833

Free counselling and advice for parents and carers in the ACT. Available Monday to Friday 9am to 5pm and Saturday 10am to 12noon.

Parentline (QLD and NT only) — **1300 30 1300**

Free telephone counselling and advice for parents and carers in Queensland and the Northern Territory. Phone line available 8am to 10pm seven days a week. Webchat available 8am to 9pm seven days a week.

Parent Line (NSW only) — 13 00 52

Free telephone counselling and support service for parents and carers with children from birth to 18 years old in NSW. The service is available between 9am to 9pm Monday to Friday and 4pm to 9pm on weekends.

Parent Helpline (SA only) − 1300 364 100

Free telephone information and support for parents and carers of children from birth to 12 years in South Australia. Available 24 hours a day.

Parent Line (TAS only) — 1800 808 178

Free telephone information and support for parents and carers in Tasmania. Available 24 hours a day.

Parentline (VIC only) — **13 22 89**

A phone service for parents and carers of children from birth to 18 years old in Victoria. Available 8am to midnight seven days a week.

Parenting Helpline (WA) — (08) 9368 9368 or 1800 111 546 for country callers.

A phone service by Ngala for parents and carers of children from birth to 18 years old in Western Australia. Available 8am to 8pm, seven days a week. Outside these hours, parents and carers can leave a message on the call-back service.

See other sections of this guide or download the complete guide here.

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Do I need to see a GP about my mental health?

This information about mental health and the role of General Practitioners (GPs) is provided to help you decide whether you need to see a GP about your mental health.

If you'd like to see a psychologist about your mental health it's a good idea to see a GP first for a referral and a Mental Health Care Plan.

If you need urgent help or life is in danger dial 000.

This isn't a crisis guide. If you're in crisis please contact

Crisis Support

- <u>Lifeline</u> **13 11 14** National free crisis counselling service. Available 24 hours a day.
- Beyond Blue 1300 224 636
 National free mental health counselling service. Available 24 hours a day.
- 1800 RESPECT 1800 737 732
 National sexual assault, domestic and family violence counselling service.
 Available 24 hours a day.
- 13 YARN 13 92 76
 National crisis support line for mob offering one-on-one yarning. 24 hours a day.

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About mental health and mental ill health

Research shows that around 60% of Autistic people experience mental ill health. For example, anxiety.

'Good mental health' is a phrase that's used a lot. Having good mental health means more than just feeling good or happy. It means being able to cope, manage and deal with challenges in everyday life. Mental ill health means not being able to cope, manage and deal with challenges in everyday life.

It's normal to feel worried, sad, overwhelmed, or lonely at times. If you have these feelings a lot and/or become overwhelmed by them, it may be a sign of mental ill health. In this resource we use the term 'mental health concerns' to mean any changes to your mental health that you or someone close to you are worried about.

Making an appointment with a GP is a good place to start if you have concerns about your mental health.

Signs of mental ill health, including differences in Autistic people

Mental ill health or mental health concerns can look and feel different for Autistic people.

Some of the common lists and descriptions of mental health symptoms may not reflect your experiences, or the way you usually feel. For example, 'downhearted' or 'blue' to describe low mood or sadness.

You may have noticed other changes. You may be more sensitive to some things in the environment or need more input from your environment.

You may have noticed changes to eating, sleeping, and how difficult it is to leave home to go to school or work.

Sometimes it can be hard to describe your experiences, particularly when you have mental health concerns.

There are a number of resources that can help you to understand and communicate with health professionals about what your life is usually like. For example:

- Reframing Autism has videos of Autistic people talking about their behaviours and experiences.
- The National Autistic Society has resources that describe Autistic behaviours.

What can affect mental health?

A combination of your genes and your environment affect your mental health.

This means that no two people will respond to the same situation in exactly the same way. Situations that may be overwhelming and cause a lot of anxiety for one person, may seem like a small problem that's easy to manage for another person.

It's important to know that changes in your life and routine can cause changes in your mental health. You may feel more stress, anxiety, depression, or other mental health symptoms in response to different events. These events may be personal to you, or events that impact many people.

Big changes that affect you personally can trigger changes to your mental health. Some examples of big changes are the death of a family member or friend, having a baby, a relationship breakup, or changes to your work or living situation.

Global events that affect large numbers of people, like the COVID-19 pandemic, bushfires or climate change, can also trigger changes to your mental health.

Smaller changes can also affect your mental health. Some examples of smaller changes are a change to your daily routine or special interests, changes in your responsibilities at home, school, or work, changes in your relationships and who you are able to see, or changes to your support team. Even changes to your football or other sporting team may affect your mental health.

There's no right or wrong way to cope with different events. The important thing is to make sure you communicate changes you notice in how you're thinking, feeling, or behaving to someone you trust, or a health professional, for example a GP or a psychologist.

How can a GP help me with my mental health?

A GP is usually the first professional you'll see if you have concerns about your mental health.

The GP will often ask you about what's been happening in your life and may ask you to complete some mental health questionnaires.

GPs are skilled at understanding many different types of conditions. A GP will try to work out if the cause of your condition is physical, psychological, or a combination of both.

GPs can also give you information about different options for treatment. These may include medication, counselling, or ongoing sessions with a psychiatrist or an Allied Mental Health professional such as a psychologist.

If your GP recommends that you see a psychiatrist or an Allied Mental Health professional about a particular issue, they'll make a referral. They may also complete a Mental Health Care Plan. The Plan allows you to use Medicare rebates for a certain number of sessions with a range of specialists. Read more about different mental health professionals.

Rights and advocacy

You have rights when seeking help for your mental health.

Rights are basic freedoms that all people have, regardless of their sex, race, culture, gender, belief system, disability, or neurology. Your rights shouldn't be taken away from you, and it is against the law to deny people their rights in many situations.

- You have the right to be treated with dignity and respect.
- You have the right to access appropriate healthcare.
- You have the right to not be discriminated against because you're Autistic.
- Remember: Your experiences are important, and your support needs are valid!

If you feel unsupported in getting help for your mental health concerns you have the right to speak out. You can make a complaint to the health professional or practice, or you can contact the Australian Health Practitioner Regulation Agency.

What to do next

You may find the following resources helpful in deciding what to do next:

- The Support person resource describes what a support person is and times when you might choose to have a support person.
- If you'd like to explore your symptoms and signs more go to the Visual symptoms and signs resource
- If you think you need to book an appointment with a GP go to the Before the appointment checklist

Read the <u>references</u> for this resource.

See other sections of this guide or download the complete guide here.

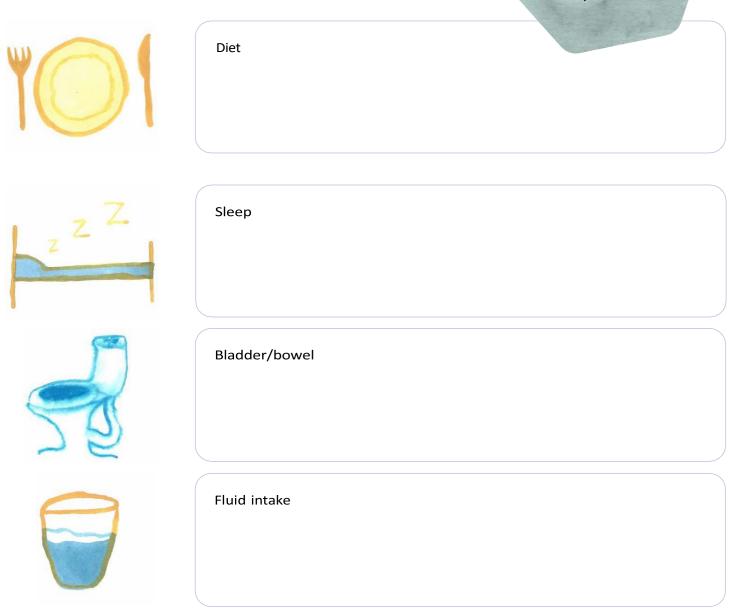


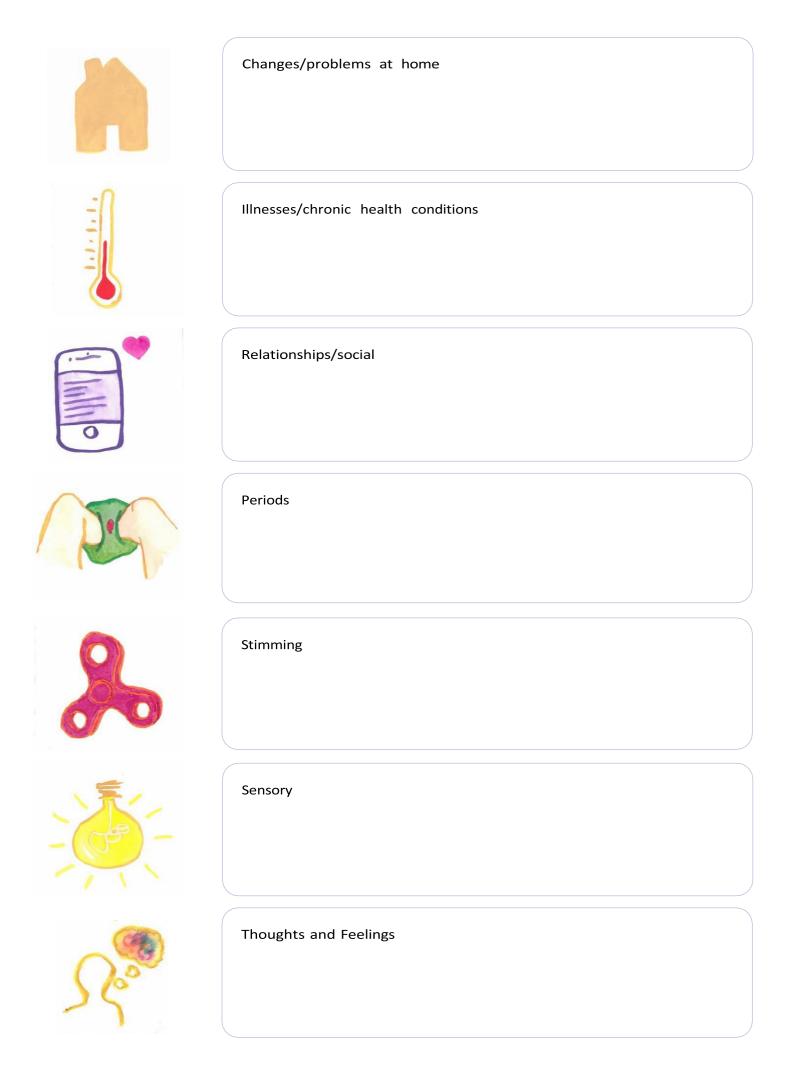
Visual Symptoms and Signs Resource

This resource is to help you think about symptoms. Sometimes when experiencing mental ill health symptoms, you may feel physical sensations or symptoms you may not link to your emotions. This may be changes in sleep, diet or pain.

Before going to the GP think about the symptoms you are experiencing and write them down. This will assist your GP with a diagnosis. It will assist you to prioritise what you would like to say to your GP.

You don't need to put something in every box. Write down any symptoms that you notice.







Support Person

Sometimes when visiting your General Practitioner (GP) or another health professional, it may be helpful or important to have a support person with you. This section answers some common questions about a support person and lists when a support person may be helpful.

What is a support person?

A support person is a person you trust that can help you to visit the GP. This person can help you with some, or all of the steps in planning and visiting a GP. Sometimes a support person may be a formal person, for example, an advocate or a support worker. Sometimes they can be a trusted family member, partner or friend.

Do I have a support person?

Some Autistic women have a support person that helps them with tasks they need support with. This may be a family member, partner, trusted friend or formal person. Sometimes when you're unwell, a friend or family member may offer to help. Or you may ask a friend or family member to be your support person. You may need to ask more than one person before you find someone who is free to help you.



"My Mum calls the clinic and books me in. That really helps when I'm not feeling well."

 Autistic woman talking about support provided by a family member.

Support Person © Amaze 2020 | 15

Can I choose whether I have a support person?

Yes, you can choose whether to have a support person. There may be times in your life when you have a support person and also times when you can manage on your own without a support person.

Times when a support person may be helpful

- When you are unwell and need physical help.
- If you feel overwhelmed or have shut down.
- To get to an appointment on time, if that's something you find hard.
- If you need someone to write down and remember things that the GP has said.
- If you need help after your appointment with the things you need to do.
- If you want some emotional support during, before, and after the appointment.

Times when a support person may not be helpful

- When you want to discuss private information with the GP that you don't want to share in front of another person.
- If a support person is pressuring you to take them when you visit the GP, or not being supportive in other ways.
- If the support person is making the situation more stressful for you.

If you want to talk about private information with the GP you may want to choose a support person who you normally wouldn't take with you. This support person may be a friend who respects your views. You can also ask your support person to support you for part of the appointment.

Support Person © Amaze 2020 | 16

My support person is being over-protective or pressuring me, what can I do?

Talk with your support person about your rights and your right to see a GP by yourself. Share the resources in the links below about rights and responsibilities. Let your support person know that you value their support and that you need some privacy. If they can't support you and your rights, you may decide to choose a different support person.

I'd like to discuss a sensitive issue with the GP without my support person present. How can I arrange this?

Let your support person know that you'd like to talk to the GP by yourself. Remind them that you have a right to privacy and that you value their support. Share the resources in the links about rights and responsibilities. If it's difficult to talk with your support person about this you can write a note to the GP. Write the note before the appointment and bring it with you when you see the GP.

For example:

Dear GP, please ask my support person to leave the room so that we can talk in private. Regards, your name

Resources on the role, rights and responsibilities of a support person

The Office of the Public Advocate has more information about appointing a Medical Support Person.

Queensland Health has a fact sheet on the rights of family, carers and other support persons.

The Australian Government Department of Health has information on rights and responsibilities of carers and support persons in the Mental Health statement of rights and responsibilities.

The next step is to work out what you want to say to the GP. The What to say to the GP worksheet is designed to help you or you can make your own notes.

If you're ready to book an appointment with a GP you can use the Examples of what to say when booking an appointment with a GP by phone.

If you've already booked an appointment the <u>Before the appointment checklist</u> can help you to get organised.

See other sections of this guide or download the complete guide here.

Support Person © Amaze 2020 | 17

What I want to say to the GP



In preparing for your appointment you can use the What to say to the GP worksheet to work out what you want to say to the GP. You can use the worksheet with your support person or by yourself.

It's a good idea for you or your support person to make some notes on your phone or on paper about what you want to say to the GP.

If you know the GP's email address, you can send them an email with a short list before your appointment. This can make it easier for you to communicate with the GP at the appointment when you're feeling unwell.

See other sections of this guide or download the complete guide here.



Before the appointment checklist

This is a checklist of the steps needed to book an appointment with a General Practitioner (GP).

On the checklist tick the column/s next to each step to show -

- what you can do (Me column),
- where you need a support person
- or where a step isn't needed.

Read more about what a support person is and times when a support person may be helpful in the support person resource.



Steps	Me	Support Person	Not Needed
Booking the appointment:			
 Decide whether to see your regular GP, or if you need to find a new GP. You may decide to see a new GP about your mental health. 			
• Find out the cost of the appointment and decide whether you can afford it. If you can't afford the cost, ask whether the clinic can bulk bill you. This is where the total cost of your appointment is covered by Medicare. Some clinics offer this. Read more about low cost health services.			
Get your diary or calendar.			
• Call the GP. —or—			
Book online.			
 Compare available times to your diary/calendar. 			
 If you're attending this clinic for the first time, you can ask about the cost and how much of the cost is covered by <u>Medicare</u>. Ask if you can fill in the clinic registration forms before the appointment. 			

Remember your mental health is important.

You may need to cancel or postpone other events in your diary or calendar to book the appointment.

Steps	Me	Support Person	Not Needed
Getting to the appointment:			
Choose the best way to get to your appointment. You may want to allow time for any possible delays or weather conditions that will affect your travel.			
Think about the best way to get home after the appointment and whether you may need support. You may choose to use a different mode of transport.			
If you're taking a support person, decide whether they'll travel with you or meet you at the clinic.			
 If you're driving, where will you park? Some clinics have carparks, some may have street parking or overflow parking at busy times. Check if you need to pay for parking. 			
 To make it easier to find the clinic, check Google street view to see what the clinic looks like from the outside. 			
 If you know that the GP often runs late, call before you leave home to see if the appointment will be on time. 			

Steps	Me	Support Person	Not Needed
You can add different steps here.			
You can add different steps here.			
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See other sections of this guide or download the complete guide here.



Examples of what to say when booking an appointment with a GP by phone

Booking a standard appointment with a General Practitioner (GP)

A standard appointment is less than 10 to 15 minutes long and usually allows time for you to discuss one or two medical concerns with a GP.



Hello, my name is [say your first name].

If the receptionist is busy you may be asked to hold. When the receptionist answers the call again you'll need to say:

Hello, my name is [say your first name].

I'm calling to book an appointment with Dr [name of GP] on [day you're available].

Or if it's urgent:

I'm calling to book an appointment with Dr [name of GP] as soon as possible please.

The receptionist will tell you the available times for that doctor. For example:

I can offer you 3pm or 4pm with Dr [name of GP] on Tuesday.

Thanks, I'd like to come at 3pm on Tuesday.

Dr [name of GP] will see you at 3pm on Tuesday. Thank you.

Thanks, Goodbye.

If you need a mental health care plan or you have a lot of mental health concerns to discuss with a GP you'll need to book a long appointment. A long appointment to prepare a mental health care plan is 20 to 40 minutes and allows time to discuss your mental health concerns with a GP.

Booking a long appointment with your GP



Hello, my name is [say your first name].

If the receptionist is busy you may be asked to hold. When the receptionist answers the call again you'll need to say:

Hello, my name is [say your first name].

I'm calling to book a long appointment with Dr [name of GP] on [day you're available].

The receptionist will tell you the available times for that GP and may ask the reason for the long appointment. For example:

I can offer you 3pm or 4pm with Dr [name of GP] on Tuesday. May I ask the reason for the long appointment?

Thank you, I'd like to come at 3pm on Tuesday. I need extra time to discuss my concerns.

You can choose to say I need extra time for a mental health care plan if you're comfortable giving the reason. You don't have to say the reason for the appointment, but it can help the receptionist to prioritise the appointment.

Thank you.

Dr [name of GP] will see you at 3pm next Tuesday.

Thanks, Goodbye.

Read the references for this resource.

Resource: Making and Managing Health and Medical Appointments

See other sections of this guide or download the complete guide here.



Appointment checklist



This is a checklist of the steps needed for an appointment with your General Practitioner (GP).

On the checklist tick the column/s next to each step to show:

- what you can do (Me column),
- where you need a support person or
- where a step isn't needed.

It's OK if you don't need some of these steps. It's OK if you need to add different steps.

Steps	Me	Support Person	Not Needed
Appointment day:			
Bring your Medicare card.			
If you have one, bring your Health Care Card.			
 Bring sensory tools or activities that will help you in the waiting room. 			
Bring notes on what you want to talk to the GP about.			
 Bring the name and contact details of a psychologist you want to see. To find one ask the GP or follow the steps in the <u>Finding</u> a psychologist resource 			
 Go to reception. If the receptionist is busy, wait for your turn. When the receptionist is free say your name and which GP you're there to see. Ask how long the wait will be. This will help you decide how and where you would prefer to wait. 			
• Wait.			
 If you're waiting outside, or in the car how will you know it's your appointment time? Ask the receptionist to call or text you. 			
 When the receptionist or GP calls you remember to bring all of your belongings with you. 			

Steps	Me	Support Person	Not Needed
After your appointment:			
 Go to reception. If the receptionist is busy, wait for your turn. 			
 Give the receptionist your Medicare Card and Health Care Card (if you have one). They may ask if you'd like them to process your Medicare claim. 			
 If you're being bulk billed, the cost is covered by Medicare and you won't have to pay anything. If not, the receptionist will tell you the amount you need to pay. 			
 If you need to make another appointment with the GP you can make it now or wait until later. 			
You can add different steps here.			
You can add different steps here.			
You can add different steps here.			

See other sections of this guide or download the complete guide here.



Finding a psychologist

If you have concerns about your mental health a General Practitioner (GP) may suggest that you make an appointment with a psychologist. A psychologist can assess your concerns about your mental health and provide support, advice and treatment.

Most GPs will ask you which psychologist you would like to see. When GPs write a Mental Health Care Plan they need to put the name of the psychologist in the plan. The plan is similar to a referral, that goes through Medicare. If you already have a good relationship with a psychologist, bring their name and contact information with you to the GP appointment.

Ask for recommendations

If you don't have a psychologist but think that the GP knows and understands you and your needs well, you can ask them for recommendations. You can also ask other Autistic people you know for their suggestions.

A recommendation, even from someone you know and trust, doesn't mean a psychologist will be right for you but it's a good place to start.

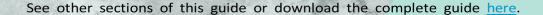
Find a new psychologist

If you need to find a new psychologist, you can visit the Australian Psychological Society (APS) website.

- Select "Autism Spectrum Disorder (incl. Asperger's)". You can also add one or two other issues you would like to talk to the psychologist about if you wish.
- Enter your location (postcode or town/suburb) to get a list of the psychologists in your area with autism expertise.

- If you don't get any results, you can broaden your location (this is set to a 5km radius by default) or remove one of your selected issues.
- If you get too many results, you can use the "Refine your search" to filter the list - some good choices are "Client Type" (ages) and "Medicare" options.
- Click on the psychologist's name or the "View full profile" button to see more information about them to help you make a decision or click on the website link under their name to view their website.
- Contact the psychologist to ask if they work with adults, whether they're taking new clients and if they're registered with Medicare.

Read the <u>references</u> for this resource.





Checklist: How I want to communicate with the GP

This checklist can help you to choose how you want to communicate with the General Practitioner (GP).

Do you want to communicate with the GP verbally?

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See other sections of this guide or download the complete guide here.

Checklist: How I want to communicate with the GP



Visiting the General Practitioner (GP)

When visiting the GP you can ask for changes to be made to meet your communication preferences and sensory needs.

Communicating with your GP

Use the Checklist: How I want to communicate with the GP to work out what the GP needs to know. You can fill in the checklist yourself, or with a support person. The completed checklist is a reminder of what to tell the GP about how you need to communicate during the appointment. For example, if you note in the checklist that you need more time to read you can let the GP know this.

During our consultation with Autistic women they generously shared their experiences for others to learn from.

- "I like to practise what I want to say to the GP. For 1 example, what's different to my usual state. It makes it easier to explain when I get to my appointment."
- . " In the past GPs have inferred information and I'm meant to 'fill in the blanks'. I can't do that. I need the GP to be specific and direct in the information they give me and the questions they ask."
- 9 " I ask my GP to explain why things need to happen during the appointment. For example, why do I need to fill out this mental health questionnaire? It helps me to understand."

Take notes or ask the GP or your support person [Link to support person] to write down or email, information from your appointment. For example, notes about treatment, referrals, medication, other health advice and what you need to do after the appointment. The free Abridge App is listed in the Resources section. It can be used to record conversations with the GP and other health professionals. Ask the GP if it's OK to record the conversation and get their consent before you start recording.

Asking for written information

When the GP has finished asking questions, they will probably give you information about what is happening and make some suggestions to help with your mental health.

You can ask the GP to write down the information and suggestions to help you remember.

The main things you need to know are:

- **New information:** The GP should write down any diagnoses, test results, or other new information from this visit, or since your last visit.
- 2. **Changes to treatment:** This means any new medications, as well as any changes to the dose of your medications or how often to take them. It may also include new doctors or other professionals they think you should see.
- Follow up: When should you see the GP again? Do they want you to have any blood tests or scans? How do you contact new health professionals for an appointment? If making appointments is hard for you, the GP or the receptionist may be able to book it for you and give you the information.

The GP may need to do a physical examination of your body to check your health or to diagnose an illness or injury. The GP needs to get your consent before examining you. They should tell you which parts of your body they'll examine, why they want to examine you and what will happen during the examination. You can ask the GP any questions before giving your consent and also ask to have your support person with you during the examination. Read more about physical examination by a doctor.

Sensory needs

What are your sensory needs? You may already have strategies or tools that you use to manage your sensory needs.

Some of your needs may be met by asking the GP or receptionist to make changes for example, giving you a quiet area to wait. Others may be met by using strategies or tools, for example, listening to music or a podcast with headphones, using a fidget toy, wearing tinted glasses or sunglasses.

Pack items for your sensory needs. You may have already decided on sensory tools when completing the before your appointment checklist.

During our consultation with Autistic women they generously shared their experiences for others to learn from.

- "Sometimes I've travelled on noisy public transport, then the waiting room has a noisy TV and I get stressed. A quiet space to wait would really help me."
- " Being unwell can increase my challenges with sensory processing."
- " If a GP is wearing perfume, it's overwhelming for me."



Read the <u>references</u> for this resource.

Here are some sensory challenges and some strategies for managing them:

Light	Wear a hat, tinted glasses and/or sunglasses. Ask the GP to dim the lights or switch off fluorescent lights (this may not be possible if the light's needed for medical examinations).	
Sound	Ask the receptionist to turn off TVs and/or radios in waiting areas. Ask if any hand dryers in the bathrooms can be switched off. Wear earplugs, earmuffs, noise cancelling headphones or listen to music, or a podcast, with headphones. Either ask your support person to check you in at reception or remove your headphones to tell the receptionist that you've arrived. Take your headphones off or mute the sound when you see a GP in the waiting area so that you can hear when they call your name.	
Temperature	Dress in layers, avoid sitting near the door or close to the air conditioner/heater.	
Space	Ask for a private waiting area or wait in your car or outside and ask the receptionist to call or text you when the GP's ready.	
Touch	Tell the GP if you prefer a firm or light touch during physical examinations. Ask GP to check with you before touching you.	
Movement	Ask if there's room to move while you're waiting. For example, ask 'can I go for a walk while I'm waiting, and will you call or text me when the GP's ready?'	
Smells	Let the receptionist know that you need a low fragrance or fragrance-free environment. Ask for a private waiting area or wait in your car or outside and ask the receptionist to call or text you when the GP's ready.	

If asking for changes is difficult you could email before the appointment to ask for the changes you need, or your support person could ask for you.

See other sections of this guide or download the complete guide here.



What to say to the GP worksheet

This worksheet can help you to get ready for your appointment with the General Practitioner (GP).

Booking the Appointment

A standard GP appointment is less than 10-15 minutes long. In these appointments you'll only have time to talk about one health issue, or two if they're both simple.

If you want to discuss your mental health or get a mental health care plan, it will probably take longer. Ask the receptionist for a long appointment and ask what the cost will be.

You can tell them you need a mental health care plan, but you don't have to say what the appointment is for if you don't want to. You can say, "I'd prefer not to say."

During the appointment

The GP will ask you about your life and your health habits. You can write down some notes on this worksheet before your appointment to help you to remember and communicate clearly with the GP.

I am here to get help with:

1.	
2.	
3.	,

Even in a long appointment, you may not have time for more than three items. Always start with the most worrying or serious item on your list. This will allow the things worrying you the most to be given more attention during the appointment

Questions that may be asked

The GP may ask you if any big changes have happened in your life recently. This means things the are big or important to you. For example, someone close to you dying, moving to a new house, you pet getting sick, losing your job. Lots of other things may be big or important to you. Write down a
big changes in your life in the space below.
Write down any medications you're taking. This includes over the counter medicines and
supplements, like vitamins. Also write down any recreational drugs that you may use.
The GP may ask you about your sleep .
Write down what's normal sleep for you, and if there's been a change.
The GP may ask you about your diet . Write down what's normal for you, and if there's been a change.
write down what's normal for you, and it there's been a change.
The GP may ask you how much alcohol you drink. If you drink alcohol, write down how much you
drink each week and if there's been a change.

See other sections of this guide or download the complete guide here.

What to say to the GP worksheet



Completing mental health questionnaires

The General Practitioner (GP) may give you a mental health questionnaire to fill out during your appointment.

Mental health questionnaires have a list of questions about your symptoms and your life.

Mental health questionnaires are designed to show which type/s of mental health concern/s you may have, and how much your symptoms are affecting you. The results of mental health questionnaires give GPs information that helps them decide on what to do next.

Our research with Autistic women found that completing these questionnaires is often difficult. One of the main reasons was that the wording in mental health questionnaires can be confusing.

The research found that mental health questionnaires are often:

- unclear (for example, 'I tended to over-react to situations')
- hard to understand (for example, 'I felt down-hearted and blue')
- not linked with the experiences of Autistic women (for example, 'would you say that food dominates your life?' or 'about how often did you feel restless or fidgety?').

Tips for completing mental health questionnaires:

- answer fully and honestly, even if this means giving a bit more detail. For example: if you are often fidgety, but this isn't associated with anxiety, say so. If you never sleep well or have always found 'simple' things to be an effort; if some symptoms are new, and some have been with you all your life, say so.
- if you don't understand the question, ask the GP to explain it using plain language.
- let the GP know if you need extra time to read and answer the questions.
- if you have communication preferences, ask the GP to change the way you receive the questions (for example, have them read to you, complete them on paper or complete them online etc).
- ask the GP if you can take the questionnaires home to complete, if that's easier for you.
- use the notes you've made before the appointment to help you answer the questions. For example notes from the Visual signs and symptoms resource and/or the What to say to the GP worksheet.

- if you have a support person, ask them to help you. For example, ask them to read the questions to you.
- If your support person knows you well, ask them about any questions you are finding it hard to answer. Sometimes another person can see things that are not obvious to you.

See other sections of this guide or download the complete guide here.



Do you need to make another appointment with a General Practitioner (GP) about your mental health concerns?

This checklist is designed to help you to decide if you need to book another appointment with a GP about your mental health concerns after your appointment. This can be hours, days, weeks, months or years, after the first appointment depending on your situation.

If you need urgent help or life is in danger dial 000.

This isn't a crisis guide. If you're in crisis please contact

Crisis Support

- <u>Lifeline</u> **13 11 14** National free crisis counselling service. Available 24 hours a day.
- Beyond Blue 1300 224 636 National free mental health counselling service. Available 24 hours a day.
- 1800 RESPECT **1800 737 732** National sexual assault, domestic and family violence counselling service. Available 24 hours a day.

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Do you need to book another appointment with a GP about your mental health concerns?

Question	Yes	No
Do you have any new symptoms?		
Are you feeling unwell?		
Do you need a prescription for medication?		
• Are there any problems with the treatment?		
Do you have a question about treatment?		
Is there another reason?		

Note: If there is another reason but you're unsure about booking an appointment with a GP you can call the medical clinic to ask for advice or call the healthdirect hotline on 1800 022 222 to speak to a registered nurse. The hotline is available 24 hours a day.

If you answered **yes** to one or more of these questions, book an appointment with a GP. If you answered **no** to all of these questions, you don't need to book an appointment with a GP now.

You can come back and do this checklist whenever you want to decide if you need to book an appointment with a GP.

If you've decided to book an appointment with a GP read the examples of what to say when booking an appointment with a GP by phone.

You may like to book an appointment with a different GP. You may like a second opinion about the treatment or perhaps the first GP didn't listen to your concerns. To find another GP you can ask friends, local autism peer groups or autism online groups for recommendations. Read more about things to consider when choosing a GP.

There's a list of websites and resources in the resources section with more information about autism, mental health and helplines.

See other sections of this guide or download the complete guide here.



After your appointment

This resource will help you make sure you have everything you need to follow up on things you need to do after the appointment.

1.	Before you leave the GP clinic				
	Make sure you understand what the GP has told you, who to contact if you have questions or difficulties with the instructions.				
	Make sure you have all prescriptions, referral letters and forms for tests or scans that the GP (General Practitioner) has recommended. You also need to know how quickly you need to see another professional or have tests or scans done.				
	Make another appointment with your GP if they asked you to.				
	Put the new appointment in your phone, diary or other reminder system.				
2.	Immediately after leaving the appointment Do something that helps you to rest and recharge.				
	"After an appointment I can feel overloaded. I manage this by having some quiet time before travelling home."				
	To help you understand your treatment plan better, it may be useful to discuss this with your support person or a trusted person. If you have any concerns or queries, go back to the psychologist or the GP to get the information you need or seek a second opinion from another psychologist or GP.				
3.	Following up after the appointment				
	If you were given new prescriptions:				
	Take these directly to the pharmacy to get the medications.				
	If the pharmacy doesn't have the medication available when you go there, you may need to collect them later that day or the next day.				
	Set a reminder to take the medications (or add them to your current medications and reminder).				

If you were given forms for blood tests or scans:

- Be sure you know if these need to be done at a certain time of day or with any instructions (for example, before you eat).
- Make an appointment if required or ask your support person to make the appointment. Get these done as soon as possible.
- Contact the GP clinic to check on the results if you haven't heard in a week. They may not contact you automatically. (Many clinics will ask you to come in for an appointment rather than give private medical information over the phone).
- Share information about the appointment follow up with your support person. You can ask for help in booking appointments and organising tests if you need it.

If you need to find a new psychologist read the finding a psychologist resource. If the GP has referred you to another Allied Mental Health professional you can use these links to find:

- a mental health social worker
- a mental health occupational therapist, select 'mental health' as the Area of Practice in the dropdown menu.

For a worksheet that outlines the steps download the After the visit worksheet from the AASPIRE healthcare toolkit.

Helpful strategies

Ask my support person to help me remember to take my medication.

Set a reminder in the calendar in my phone for my next appointment or to take my medication.

Read information from my appointment about my treatment & follow inst**th**ctions

Ask my GP to send the referral to the psychologist or specialist.



"I put reminders for medical appointments in my phone and sync it to my fitbit. It buzzes when there's a reminder."

Resources



If you need urgent help or life is in danger dial 000.

Crisis Support

- <u>Lifeline</u> 13 11 14
 National free crisis counselling service. Available 24 hours a day.
- Beyond Blue 1300 224 636
 National free mental health counselling service. Available 24 hours a day.
- 1800 RESPECT 1800 737 732
 National sexual assault, domestic and family violence counselling service.
 Available 24 hours a day.
- Parentline (ACT only) (02) 6287 3833
 Free counselling and advice for parents and carers in the ACT.
 Available Monday to Friday 9am to 5pm and Saturday 10am to 12noon.
- Parentline (QLD and NT only) 1300 30 1300
 Free telephone counselling and advice for parents and carers in Queensland and the Northern Territory. Phone line available 8am to 10pm seven days a week. WebChat available 8am to 9pm seven days a week.
- Parent Line (NSW only) 13 00 52
 Free telephone counselling and support service for parents and carers with children from birth to 18 years old in NSW. The service is available between 9am to 9pm Monday to Friday and 4pm to 9pm on weekends.
- Parent Helpline (SA only) 1300 364 100
 Free telephone information and support for parents and carers of children from birth to 12 years in South Australia. Available 24 hours a day.
- Parent Line (TAS only) 1800 808 178
 Free telephone information and support for parents and carers in Tasmania.
 Available 24 hours a day.
- Parentline (VIC only) 13 22 89
 A phone service for parents and carers of children from birth to 18 years old in Victoria. Available 8am to midnight seven days a week.
- Parenting Helpline (WA) (08) 9368 9368 or 1800 111 546 for country callers. A phone service by Ngala for parents and carers of children from birth to 18 years old in Western Australia. Available 8am to 8pm, seven days a week. Outside these hours, parents and carers can leave a message on the call-back service.

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Online Resources for Autistic people

Molehill Mountain app by Autistica

This apps helps Autistic people to understand the causes and symptoms of anxiety.

Know Your Normal Toolkit by Ambitious About Autism

An online resource for Autistic young people to learn what their normal is. This helps them to develop skills to notice when there are changes in their mental health.

AASPIRE healthcare toolkit for Autistic adults

An American resource to help Autistic adults access primary health care (General Practitioners). Please note that some sections aren't relevant to Australian health care.

You Feel like Shit

This online resource helps people understand why they are not feeling great. It looks at self-care, but also emotional distress.

Abridge App (Apple Apps Link) (Google Play Link)

This app allows you to record a medical appointment. The app then turns your audio into text and creates notes from your appointment. This helps you to remember and follow up on things mentioned by the GP during the appointment.

Books

 The Guide to Good Mental Health on the Autism Spectrum by Jeanette Purkis, Dr Emma Goodall and Dr Jane Nugent. Jessica Kingsley Publishers, 2016.

Amaze

- Medicare benefits over 13 years Information Sheet
 Information about Medicare benefits for Mental Health care plans.
- Contact the Amaze Autism Connect advisors for more information about autism, or to talk about your individual situation:

Phone: 1300 308 699

Email: info@autismconnect.org.au

Website and webchat: www.amaze.org.au

This service is available from 8am to 7pm, Monday to Friday

(excluding public holidays).

See other sections of this guide or download the complete guide here.

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References



About this resource

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Ethical approval was granted by the Deakin University Human Research Ethics Committee (project no: 2019-101). This was in accordance with the ethical standards of the national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all participants. No monetary incentives were offered to participants.

Do I need to see a GP about my mental health? resource

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Examples of what to say when booking an appointment by phone resource

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 search results for Item 23 Level B. Retrieved from
 https://www.betterhealth.vic.gov.au/health/servicesandsupport/making-and-managing-health-and-medical-appointments

Visiting the GP resource

Isaacs, K.A. (2018). Access Health Autism Patient Resources: Medical Appointment Form.

Finding a psychologist resource

 Australian Psychological Society. (2020). Assessment and therapy. Retrieved from https://www.psychology.org.au/for-the-public/about-psychology/What-does-a-psychologist-do/ Assessment-and-therapy-(1)

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