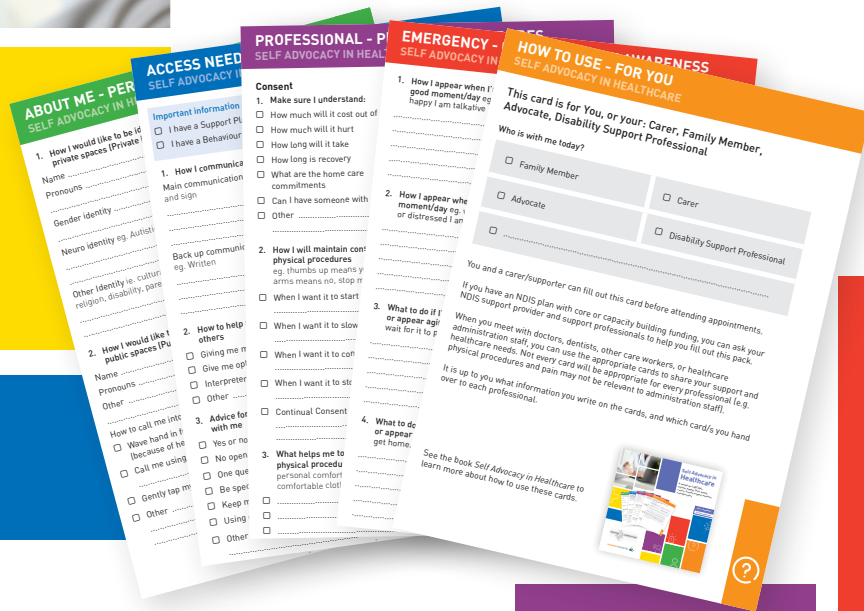


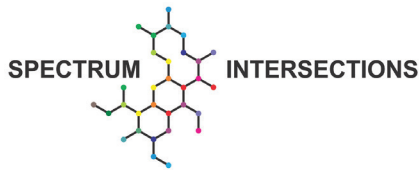
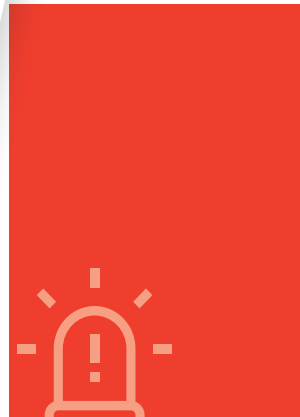
Self Advocacy in Healthcare

A toolkit for LGBTIQA+ autistic people, their family, carers, friends, support workers, and advocates



PLAIN LANGUAGE

EASY LANGUAGE





About Spectrum Intersections

Spectrum Intersections is a peer led group for people 18+ who identify as lesbian, gay, bi+, trans, gender diverse, intersex, queer or asexual+ (LGBTIQ+) and as being on the neurodiversity spectrum, which includes but is not limited to autism spectrum, attention deficit / hyperactivity condition, tourette's syndrome, obsessive compulsion, dyslexia, dyspraxia, dyscalculia, epilepsy, and other conditions that lead to brain functioning that is not neurotypical.

Members do not require a medical diagnosis of autism or neurodiversity to attend the free peer group, and recognises the current access barriers that exist in gaining diagnoses. Spectrum Intersections is a safe space and learning environment for people without fear of judgement, misunderstanding, harassment or abuse.

Spectrum Intersection provides connection, advocacy, and education to:

- ▶ LGBTIQ+ neurodiverse people, their friends, families, and supports
- ▶ Community advocacy through board representation
- ▶ Professional spaces through training and workplace/service consultancy
- ▶ Visit www.spectrumintersections.org for more information



About Inclusion Designlab

Inclusion Designlab is Inclusion Melbourne's centre for policy, research and development, and quality. Its vision is to bring together people with a disability, community organisations, government, and the world's leading disability researchers to develop cutting-edge models of practice, choice and citizenship.

It does this by developing, trialling, and implementing new systems of support and communicating its insights through a range of media. Inclusion Designlab is also a significant contributor to public policy and inquiries. Its focus areas include LGBTIQ+ inclusion, oral health, voting, political citizenship, and access to justice.

Visit www.inclusionmelbourne.org.au/designlab for more information

This resource is part of a project funded by Pride Foundation Australia and Sidney Myer Foundation.

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Preface

Spectrum Intersections supports lesbian, gay, bi+, trans, gender diverse, intersex, queer, and asexual+ (LGBTIQQA+) neurodivergent people to experience social inclusion and belonging in their communities, with a focus on understanding that LGBTIQQA+ and neurodivergent identities are core to personal identity, expression, communication, and connection.

This approach to inclusive support is aligned with the Disability Act Vic (2006), the UN Convention on the Rights of Persons with Disabilities (2006), the National Disability Insurance Scheme Act (2013), Mental Health Act Vic (2014), Victorian Human Service Standards and evidence based practices such as Person Centred Active Support.

This resource was developed in response to the needs of LGBTIQQA+ autistic communities, including members from Spectrum Intersections and beyond.

Due to the different expressions of the autistic experience, many autistic people feel misunderstood during medical appointments and healthcare treatment. This, combined with healthcare access issues faced by members of the LGBTIQQA+ community, can result in LGBTIQQA+ autistic people struggling to have their basic healthcare needs met.

“I often feel judged by doctors. It’s like I’m sitting a test, where I have to prove to them that I am unwell enough to receive help ... I would love to feel like doctors are partnering with me to improve my health so that I can be empowered to participate in the experience.”

- Focus group participant

Many people from this group report avoiding making appointments with healthcare professionals due to administrative barriers, communication barriers, as well as financial barriers.

This toolkit has been co-designed by autistic LGBTIQQA+ people for autistic LGBTIQQA+ people to allow them an opportunity to self advocate through the healthcare system.

The resources that comprise *Self Advocacy in Healthcare* are designed to bridge the gaps between autistic LGBTIQQA+ individuals and healthcare professionals within a patient centred multidisciplinary model and ensure informed consent is met.

Regarding language, the identity first term *autistic person* has been chosen over *person with autism*. While there is a clear division globally regarding the terms *disabled person* and *person with disability*, with the exception of *person with intellectual disability* where person first language is dominant, the autistic community is far less divided. Self advocates regularly indicate their preference for identity first, rather than person first, language.

How to read this book




Self Advocacy in Healthcare is designed for **supported reading**.

Most of the left-hand pages are written in plain language. The right-hand pages are written using easy language. This means that the text uses larger letters and there are pictures or diagrams to assist supported readers.

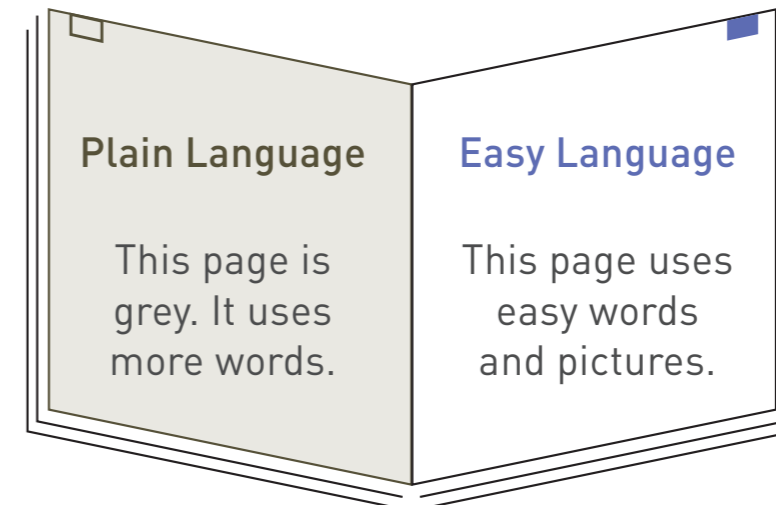
If you don’t find reading difficult, you can read the left hand pages by yourself. If you need support, you can ask your supporter to read the left-hand pages then help you read the right-hand pages.

In most cases, the ideas on the left and the right are the same.

You will see this picture  next to **bolded** words you may not understand. There is a glossary at the back of the book. The glossary tells you what these words mean.

These boxes are for family carers, friends and advocates who may be reading this book on behalf of another person.

This symbol has been used to signify sections written specifically to be read by healthcare professionals. They will also be highlighted in light pink boxes.



Experiences in Healthcare

We know that LGBTIQ+ autistic people experience greater difficulty in accessing healthcare that meets their needs.

Research looking at Healthcare experiences of autistic adults^{1,2} has indicated that accurate and effective care and treatment of autistic people can be met by providers through:

- ✓ Respecting and adapting to different communication styles and needs
- ✓ Increasing understanding of autistic experiences and needs
- ✓ Provision of accommodations when requested
- ✓ Tackling stigma and stereotypes about autistic people
- ✓ Reducing assumptions about individual patients

Current and past experiences of assessments during an emergency situation has led to some autistic people being incorrectly labelled as behaving erratically, drug seeking, or dangerous while experiencing distress.³ These experiences are compounded for autistic people who have a non-speaking/non-verbal communication style, or who become non-speaking during times of crisis or stress.

Additionally, when working with the LGBTIQ+ Community we know that historical experiences of discrimination and ignorance impact their willingness to access healthcare services⁴⁻⁸.

Intersectionally, LGBTIQ+ autistic people sit in the middle of both of these experiences, making them a uniquely vulnerable population. Being able to feel supported in making decisions about their medical needs in partnership with healthcare professionals can improve healthcare participation and outcomes in this population.

This is about building good relationships, demystifying complex communication, and overcoming tension and difficult emotions.

Traditional common conceptions of Autism include a main feature of deficits in communication compared to **Allistic** ⁺ people⁹. However, current research is beginning to show that autistic styles of rapport and communication are effective when between autistic individuals, and it is when communication occurs between different neurotypes that extra care must be taken to prevent misunderstandings¹⁰.

Experiences in Healthcare

It can be really difficult for some autistic people to get help for their health. Sometimes health professionals, doctors, dentists, and mental health workers can find it hard to understand autistic people.

Here are some of the wrong things that some people think about autistic people:

- ✗ Autistic people behave in a way that is dangerous or scary
- ✗ Autistic people visit health professionals for dishonest reasons. For example, to get extra medication they don't need.
- ✗ Autistic people can't communicate properly

When autistic people are worried about being seen this way, they may choose to not seek help for their health. They may also feel worried about how they will feel when they go to the doctor's office or the hospital. This is because some of these places have noises, light, people or other things that can make it hard for them to cope.

Researchers and experts are learning more about how to change this. Many doctors and other health professionals are taking time to learn about autism and autistic people. This is really good! It will make it easier for autistic people to get help for their health.



You can share this book with your doctors to help them learn about autism and autistic people.

Disability and Support

There are so many ways of viewing disability. From the British social model of disability, to American civil rights approaches and Nordic relational approaches, the late 20th century saw a shift away from viewing people with disability simply through the lens of medical diagnoses to an approach that emphasised the removal of barriers, addressing the mismatch between person and environment, and working to ensure inclusion in each situation or context.

In recent times, researchers and experts have worked to apply these models to the experiences of autistic people. This has involved acknowledging that, in addition to the removal of physical, social and sensory barriers, people with cognitive disability also require support and inclusion through dynamic, empowering, and human-rights strengthening relationships. This is particularly relevant for people for whom the direct support and advocacy of others is required on a regular - or

daily - basis¹¹. It has also involved designing buildings that cater for all people's needs, and planning new healthcare processes that ensure everyone has a good experience. We also see the outworking of this approach in Circles of Support, peer support, self-advocacy, and Supported Decision Making. *Self Advocacy in Healthcare* has been written with these ideas in mind.

Self Advocacy in Healthcare has also been written according to principles of Patient Centred Care and inter-disciplinary approaches. This sounds complex, however it can be explained easily. It means that you get to be in control of your care. You get to understand what your diagnoses are, what your treatment is, who treats you, and how you feel about it. It also means that your health professional should speak to other health professionals in your life to make sure they understand you properly - with your permission.

Patient Centred Care

This publication assumes that healthcare professionals will abide by Patient Centred and inter-disciplinary approaches. Here is a great overview of Patient-Centred Care from the Victorian Government's Better Health website.

www.betterhealth.vic.gov.au/health/servicesandsupport/patient-centred-care-explained



Disability and Support

It is your right to get the healthcare you need. This includes help from doctors, dentists, psychologists, therapists, and many others. These health professionals need to:

- ▶ Work with you to make sure you are able to visit them easily
- ▶ Take time to understand your needs
- ▶ Take time to understand how you communicate
- ▶ Take time to learn about autism
- ▶ Read any information about you that you give them
- ▶ Let you make decisions about yourself
- ▶ Speak to other health professionals who know you - but only if you want this
- ▶ You can ask for support from other people to do any of the things in this list.

You have a right to say Yes or No to healthcare treatment. You get to be in charge of your care. You also have a right to ask lots of questions if you need to. You also get to decide WHO treats you and to change your mind if you want to.



Using the Toolkit

The toolkit has been designed with 3 parts:

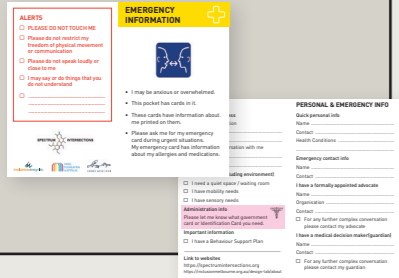
1

This book - How to use self advocacy in healthcare



2

Wallet Card - A small card that fits in your pocket or wallet



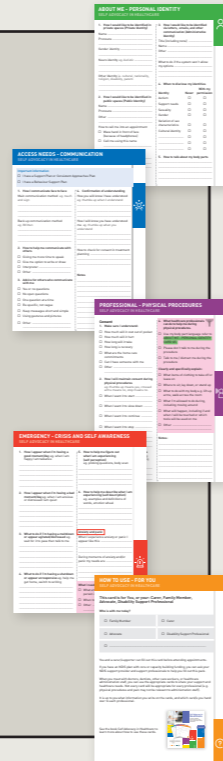
3

Personal Infocards: There are 4 fillable cards and 1 smaller information card. These come in a cardboard pocket. You can use these to record your personal information and access needs, to help you advocate for yourself.

- a) About Me - Identity Information / Appointment Needs
- b) Access Needs - Communication / Environmental
- c) Professional - Physical Procedures / Pain
- d) Emergency - Crisis and Self awareness / Medication and Allergies
- e) How to Use card - For You / For Professionals

Each section is fillable with options for you to write in what your personal needs are, and/or pick and choose from options provided.

Sections 2 and 3 can be filled in individually or with a supporter



For supporters

You can help the person you are supporting fill out the cards, but keep in mind it is up to them to direct and decide what is written on them and how this is done.

For healthcare workers

These cards are individualised and personal so the information on them may not be relevant to the work that you do. It is up to the person to choose if they want to share this information with you.



Using the Toolkit

This toolkit has 3 parts

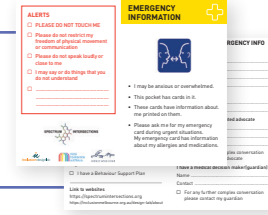
1

This book - How to use *Self Advocacy in Healthcare*



2

Wallet card - You can carry this card in your pocket



3

Personal Infocards - You can fill out these cards by yourself or with support. You can show them to your doctor, dentist, or other health professionals. You can use them to help you talk about your needs, body, health, and treatment.

a	About Me - Identity Information / Appointment Needs
b	Access Needs - Communication / Environmental
c	Professional - Physical Procedures / Pain
d	Emergency - Crisis and Self awareness / Medication and Allergies
e	How to Use - For You / For Professionals

You can ask these people for help:

- ▶ Friends or family
- ▶ Disability support professionals
- ▶ People in your circle of support
- ▶ An advocate

These cards are yours to take with you when you go to visit your doctor, dentist, or other health professionals. You can choose who sees these cards. If you don't want to show a card to someone, you don't have to!

About the Yellow Wallet Card



Autistic people interpret and express their experiences of the world in ways that some people find difficult to understand.

This can include:

- ▶ **Communication** - Verbal and non-verbal, body language, and interpretation of colloquialisms, idioms, and metaphors.

- ▶ **Social Interaction** - Understanding intentions and awareness of self and others

- ▶ **Sensory Processing** - Experiences within the physical environment that might be hyper or hypo sensitive to sound, smell, sights (lights and colours), touch, and pain

- ▶ **Behaviour** - Including repetitive behaviour, response to stimuli, and reaction to situations

As autistic and LGBTIQ+ needs are not obvious from looking at someone, having a quick access card that allows people to identify their varying priority needs quickly and simply can be helpful.

This card would not be used as a thorough guide of what people's needs are but to help identify potential barriers to service.

Target Audience: First Responders, such as paramedics or doctors, reception staff, and advocates.

EMERGENCY INFORMATION



- I may be anxious or overwhelmed.
- This pocket has cards in it.
- These cards have information about me printed on them.
- Please ask me for my emergency card during urgent situations. My emergency card has information about my allergies and medications.

About the Yellow Wallet Card

In an emergency, we sometimes need people to know things about us so they can help us quickly.

The Yellow Wallet Card is something you can show to someone when there is an emergency. It fits in your pocket.

This card lets people know:

- ▶ You might have a hard time telling people that something is wrong Please find stock mini-graphics

- ▶ What your name is

- ▶ Who they can talk to if they have questions about you

- ▶ That you have more information on the other cards

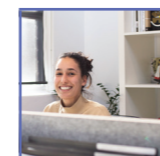
Here are some of the people you might give the card to in an emergency:



Doctor



Ambulance



Receptionist



Advocate



EMERGENCY INFORMATION



- I may be anxious or overwhelmed.
- This pocket has cards in it.
- These cards have information about me printed on them.
- Please ask me for my emergency card during urgent situations. My emergency card has information about my allergies and medications.

Yellow Wallet Card

Front and Back

The front of the wallet card has a yellow heading Emergency Information and has a cross on it. It also has the symbol for communication access



Additionally it has some general information that might be relevant in an emergency, and identifies that the Wallet Card is part of a pack that contains more information including allergies and medication information.

The back of the wallet card has alert information, including common experiences and needs that autistic people would like emergency workers to know. Each section has boxes that can be checked to indicate if you want people to follow special instructions or not. There is also a space for you to fill in your own unique instructions.

It also has the logos of the organisations that were involved in creating this card.

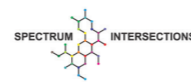
EMERGENCY INFORMATION



- I may be anxious or overwhelmed.
- This pocket has cards in it.
- These cards have information about me printed on them.
- Please ask me for my emergency card during urgent situations. My emergency card has information about my allergies and medications.


ALERTS

- PLEASE DO NOT TOUCH ME
- Please do not restrict my freedom of physical movement or communication
- Please do not speak loudly or close to me
- I may say or do things that you do not understand
-
-
-



Yellow Wallet Card

Front and Back

The Yellow Wallet Card is for emergency information. You can give this to people during an emergency. It has a little cross on it. 

It uses this picture. It lets people know that you might have a hard time communicating with other people.



It also lets other people know that:

- ▶ You might act differently to other people
- ▶ You have a pack with more cards in it
- ▶ You might have information about allergies and medication

The back of the card lets you tell people:

- ▶ If you don't like to be touched
- ▶ That you want to be able to move around and communicate
- ▶ That you don't like it when people talk loud or close
- ▶ That you might do or say things that they might not understand

You can write other important information on it.

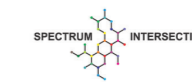
EMERGENCY INFORMATION



- I may be anxious or overwhelmed.
- This pocket has cards in it.
- These cards have information about me printed on them.
- Please ask me for my emergency card during urgent situations. My emergency card has information about my allergies and medications.

ALERTS

- PLEASE DO NOT TOUCH ME
- Please do not restrict my freedom of physical movement or communication
- Please do not speak loudly or close to me
- I may say or do things that you do not understand
-
-
-



Yellow Wallet Card

Inside

The inside of the card is broken down into access needs and important information about you.

It consists of fillable spaces and checkboxes for you to let people know your personal information, access needs and preferences. This includes:

Communication Access: How to best get your attention and how to have a conversation with you.

Physical Access, including environment: If you have physical access requirements such as mobility needs, needing a quiet space, or sensory needs.

Administration information: Whether there are government or identification cards that healthcare professionals need from you. This could be a concession or health care card, medicare card, ambulance membership, or something else.

Important Information: To let others know if you have other needs or plans, including a **Behaviour Support Plan**.

Quick Personal Information: What name you use, contact number and any relevant health conditions.

Emergency Contact Information: Name and contact details of someone to contact during an emergency situation.

I have a formally appointed advocate: Name, organisation, and contact details of your formally appointed advocate, if you have one.

I have a Medical Decision Maker (guardian): Name and contact details of a medical decision maker/guardian, if you have one.

Additionally there are checkboxes that can be used to indicate that complex conversations need to be held with either your advocate or guardian present.

ACCESS NEEDS	PERSONAL & EMERGENCY INFO
Communication access How to get my attention How to have a conversation with me Physical access (including environment) <input type="checkbox"/> I need a quiet space / waiting room <input type="checkbox"/> I have mobility needs <input type="checkbox"/> I have sensory needs Administration info Please let me know what government card or Identification Card you need. Important information <input type="checkbox"/> I have a Behaviour Support Plan Link to websites https://spectrumintersections.org https://inclusionmelbourne.org.au/design-lab/about	Quick personal info Name Contact Health Conditions Emergency contact info Name Contact I have a formally appointed advocate Name Organisation Contact <input type="checkbox"/> For any further complex conversation please contact my advocate I have a medical decision maker(guardian) Name Contact <input type="checkbox"/> For any further complex conversation please contact my guardian

Yellow Wallet Card

Inside

The inside of the Yellow Wallet Card lets you tell other people about you. You can use this card to tell healthcare professionals the most important information about you and your needs.

You can check a box to let people know:

- ▶ If you have a **Behaviour Support Plan**
- ▶ If you need a quiet space or room
- ▶ If you have trouble moving around
- ▶ If you are sensitive to things

To help others learn about you, you can write down:

- ▶ How you want people to get your attention
- ▶ How you like to have a conversation with people
- ▶ What your name is
- ▶ If you have a health condition
- ▶ Who to talk to in an emergency
- ▶ If you have an advocate
- ▶ If you have a medical decision maker

There are also boxes to let people know that you need an advocate or guardian with you during hard conversations and big decisions.

ACCESS NEEDS	PERSONAL & EMERGENCY INFO
Communication access How to get my attention How to have a conversation with me Physical access (including environment) <input type="checkbox"/> I need a quiet space / waiting room <input type="checkbox"/> I have mobility needs <input type="checkbox"/> I have sensory needs Administration info Please let me know what government card or Identification Card you need. Important information <input type="checkbox"/> I have a Behaviour Support Plan Link to websites https://spectrumintersections.org https://inclusionmelbourne.org.au/design-lab/about	Quick personal info Name Contact Health Conditions Emergency contact info Name Contact I have a formally appointed advocate Name Organisation Contact <input type="checkbox"/> For any further complex conversation please contact my advocate I have a medical decision maker(guardian) Name Contact <input type="checkbox"/> For any further complex conversation please contact my guardian



About Personal Infocards

There are 4 fillable Personal Infocards in a cardboard pocket. These cards hold important information about you. There is also an information card for supporters and professionals.

The pocket itself has the title and symbol for communication access. It also has a space on the back for a doctor approval stamp and contact details.

The cards are colour coded and each one has a unique symbol and title at the top for quick recognition. They each contain different information which can be shown to a healthcare professional if you would like to share the information.

The cards are:

Green About Me Card

- ▶ Side 1: Personal Identity Information
- ▶ Side 2: Appointment Needs

Blue Access Needs Card

- ▶ Side 1: Communication Access needs
- ▶ Side 2: Environmental Access needs

Purple Professional Card

- ▶ Side 1: Physical Procedures Information
- ▶ Side 2: Personal Pain Information

Red Emergency Card

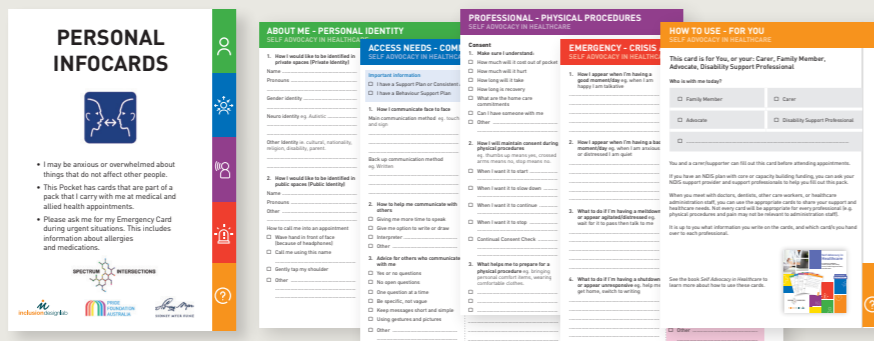
- ▶ Side 1: Crisis and Self awareness Information
- ▶ Side 2: Medication and Allergies Information

Orange How to Use Card

- ▶ Side 1: For Individuals, Supporters, Advocates
- ▶ Side 2: For Professionals

The target audiences for these cards vary based on the information on them. Some cards are helpful for being able to safely access premises, however some cards are more helpful when receiving medical treatment.

These cards have been designed to help you to advocate for yourself as a consumer of healthcare services.



About Personal Infocards

Everybody has a right to make choices about their health.

Looking after your health can be tricky. It is important for you to feel happy and safe at a medical appointment. To make sure you do, the dentist or doctor needs to know a few things about you.

The Personal Infocards are coloured cards that you can take with you when you visit your doctor, dentist or another healthcare professional.

The Green Card lets people know things about you like:

- ▶ Your name, and what you want people to call you
- ▶ Your gender
- ▶ What type of appointment to book and what you can afford
- ▶ What you want people to tell you

The Blue Card lets people know things about you like:

- ▶ If you have a Support Plan or Behaviour Support Plan
- ▶ How you communicate with others
- ▶ How to know if you understand
- ▶ How to help make a room better for you

The Purple Card is for professionals like doctors or dentists and lets them know:

- ▶ How to know you have given informed consent
- ▶ What helps you when you have to be touched
- ▶ What happens when you are in pain and how people can help

The Red Emergency Card lets people know things about you like:

- ▶ How you are when you are happy, sad, or mad
- ▶ What people can do or tell you when you are upset
- ▶ If you take medications or have a hard time with medication
- ▶ If you have an allergy

The Orange How to Use card helps other people understand this toolkit.

These cards are yours to take with you when you go to healthcare appointments. You choose who sees these cards.

If you don't want to share a card with someone, you don't have to!

Green About Me Card

Side 1: Personal Identity

This card allows others to know how you would like to be addressed. It is broken up into the following sections:

Private Identity: How you want healthcare professionals to talk about you in appointments and when they are alone with you.


Public Identity: How you want to be talked to in public spaces such as waiting rooms, this includes when being called into an appointment.

Administrative Identity: How you want to be known in written communication and in referrals.


Note: it also has a section for what to do if the healthcare professional's systems do not allow you to provide your correct details. For example, some Trans and Gender Diverse (TGD) people use titles and genders outside of the gender binary. They often find that outdated computer systems do not allow for titles and genders that match theirs.

When to disclose my identities: A list of different identities that you can indicate if you would like for this info to be private and never shared, or if you would like the information shared, but only with your permissions.

How to talk about my body parts: A space to describe how you talk about your body, as some people use individual language to talk about their bodies. This is especially important in the case of TGD people who might also experience **gender dysphoria** ⁺ and/or **body dysphoria** ⁺.

It is important to know what information to share about someone in public, as it is not always safe for individuals to discuss their medical needs, and identities in front of other people. 

Even if administrative staff are well trained about gender, sexuality, and sex characteristics, it does not mean that the general public are. Being able to choose when to disclose this information is an important part of self advocacy for individual safety.

ABOUT ME - PERSONAL IDENTITY
SELF ADVOCACY IN HEALTHCARE 

<p>1. How I would like to be identified in private spaces (Private Identity)</p> <p>Name</p> <p>Pronouns</p> <p>Gender identity</p> <p>Neuro identity eg. Autistic</p> <p>Other Identity ie. cultural, nationality, religion, disability, parent.</p>	<p>3. How I would like to be identified via letters, emails, and other communication (Administrative Identity)</p> <p>Title (including none)</p> <p>Name</p> <p>Other</p> <p>What to do if the system won't allow my options</p>																											
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Green About Me Card

Side 1: Personal Identity

The Green About Me Personal Identity Card lets you tell people how to talk about you and your body, this can be:

- ▶ In private, like in an appointment with a doctor.
- ▶ In public, like in a waiting room.
- ▶ In writing, like in a letter to where you live or to another doctor in a **referral** ⁺

You can write things like your:

- ▶ Name
- ▶ Gender
- ▶ Sexuality
- ▶ Medical conditions
- ▶ Cultural background
- ▶ Religion

You can also let people know when it is and is NOT OK to share information about you.

You can let people know how they can talk about your body.

You get to decide how people talk to you and about you.

ABOUT ME - PERSONAL IDENTITY
SELF ADVOCACY IN HEALTHCARE 

<p>1. How I would like to be identified in private spaces (Private Identity)</p> <p>Name</p> <p>Pronouns</p> <p>Gender identity</p> <p>Neuro identity eg. Autistic</p> <p>Other Identity ie. cultural, nationality, religion, disability, parent.</p>	<p>3. How I would like to be identified via letters, emails, and other communication (Administrative Identity)</p> <p>Title (including none)</p> <p>Name</p> <p>Other</p> <p>What to do if the system won't allow my options</p>																											
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Green About Me Card

Side 2: Appointment Access

This side of the card allows you to explain your access needs when making and keeping an appointment with healthcare providers.

It is broken up into the following sections:

How I would like to make appointments or contact the clinic:

Different checkbox options to indicate contact preferences.

Home Care Commitments: Outlines your capacity to continue your healthcare at home, and what healthcare professionals can do to support home healthcare needs (e.g. written instructions, SMS reminder to change dressings).

Financial Access: Your financial access needs, which could be receiving a printed quote for medical treatment beforehand, or only making bulk billing appointments.

Appointment Needs: What kind of appointments you need, including options for longer appointments, follow up appointments, or availability to bring a support worker, carer, or advocate.


What I need you to tell me: Your specific needs for how healthcare professionals communicate with you. This is intended to ensure adequate and effective communication between healthcare workers and individuals.

The role of Telehealth

Federal, State and Territory telehealth initiatives have been developed over the past 10 years to ensure all Australians have access to high quality medical care, regardless of remote location, physical disability, or psycho-social barriers. It is fair and reasonable for autistic Australians to expect telehealth services from their local health professionals. Telehealth capacity was given a boost during the 2020 COVID-19 crisis. In Victoria, concerns relating to a lack of access to telehealth services can be addressed to the Department of Health and Human Services (DHHS) and the Health Complaints Commissioner (HCC). See the Complaints section at the back of this book.



ABOUT ME - APPOINTMENT ACCESS
SELF-ADVOCACY IN HEALTHCARE

 1. How I would like to make appointments / contact clinics

Phone
 Email
 App
 Other _____

2. Home care commitments

Written instructions for home/ after care
 SMS/email reminders
 Medication plan for start, stop and monitor
 Other _____

3. Financial Access

Bulk Bill
 I have a Health Care / Pension / DVA / Other Concession Card
 Public only
 Private or public as available
 Private only
 Workcover supported provider
 TAC supported provider
 Itemised list
 Other _____

4. Appointment needs


Always book me long appointments
 Please book me a follow up appointment
 I will be accompanied by a support worker
 I will be accompanied by a carer
 I have an advocate
 Other _____

5. What I need you to tell me

Please communicate your thoughts, impressions, and responses clearly and literally
 Please clearly communicate when the appointment is over and when I need to leave
 Please let me know if I have not provided enough information
 Other _____

NOTES:

ABOUT ME - APPOINTMENT ACCESS
SELF-ADVOCACY IN HEALTHCARE

 1. How I would like to make appointments / contact clinics

Phone
 Email
 App
 Other _____

2. Home care commitments

Written instructions for home/ after care
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 Other _____

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Please communicate your thoughts, impressions, and responses clearly and literally
 Please clearly communicate when the appointment is over and when I need to leave
 Please let me know if I have not provided enough information
 Other _____

NOTES:

Green About Me Card

Side 2: Appointment Access

The Green About Me Appointment Access Card lets you tell people what you need to make an appointment.

You can let people know :

How you or a supporter make appointments, this could be:

By phone



By email



By app



What do you need to do after an appointment at home, this could be:

- ▶ If you need written guides or checklists on how to look after yourself
- ▶ If you need reminders by email, SMS, or phone
- ▶ If you need a medication plan
- ▶ If you need free or low cost services
- ▶ If you need long appointments
- ▶ If you need someone to come with you

You can also let people know that:

- ▶ You need people to let you know what they are thinking and feeling
- ▶ That you need them to be clear with their communication
- ▶ That they need to let you know when to leave
- ▶ If they need more information

Telehealth

You can ask your doctor if you can have your appointment over the phone or video. This is available for people who live far away, or cannot get to their appointments because of disability, mental health, or self-isolation.



Blue Access Needs Card

Side 1: Communication



This side of the card allows you to explain what kind of communication works best for you.

It is broken up into the following sections:

Important Information about planning documents:

- ▶ **Support plan** ⁺
- ▶ **Consistent Approaches plan** ⁺
- ▶ **Behaviour Support Plan (BSP)** ⁺

These are explained further in the glossary section of this document.

How I communicate face to face: What the best method of communicating with you is and an alternate communication method when the first is not available.

How to help me communicate with others: Communication allowances that can help you when you are communicating with healthcare professionals, if relevant. This includes giving you more time to talk and/or listen, options to write or draw, and use of an interpreter.

Plan for others communicating with me: Actions healthcare professionals can take which can improve communication with you, such as using yes or no questions, keeping messages short and simple, or asking only one question at a time.

Confirmation of understanding: For both you and the healthcare worker to figure out how to let the other know that they understand what is being communicated.

How to check for consent in treatment planning: For further information about informed consent and maintaining consent, refer to [Purple Card - Physical Procedures](#)

Less eye contact does not mean we are being dishonest or unempathetic, autistic people often experience discomfort and intensity with sustained eye contact.



Please note that autistic people often communicate via **echolalia** and **delayed echolalia**, it is important to not misconstrue this type of communication as acknowledgement of understanding or agreement.

Ensure that the autistic individual has the opportunity to talk first, as it can help avoid **echolalia** and **echopraxia** responses.

ACCESS NEEDS - COMMUNICATION SELF ADVOCACY IN HEALTHCARE	
Important information <input type="checkbox"/> I have a Support Plan or Consistent Approaches Plan <input type="checkbox"/> I have a Behaviour Support Plan	
1. How I communicate face to face Main communication method eg. touch and sign _____ _____ Back up communication method eg. Written _____ _____	4. Confirmation of understanding How you will know I have understood eg. thumbs up when I understand _____ _____ How I will know you have understood me eg. thumbs up when you understand _____ _____
2. How to help me communicate with others <input type="checkbox"/> Giving me more time to speak <input type="checkbox"/> Give me option to write or draw <input type="checkbox"/> Interpreter <input type="checkbox"/> Other _____	How to check for consent in treatment planning _____ _____ Notes _____ _____
3. Advice for others who communicate with me <input type="checkbox"/> Yes or no questions <input type="checkbox"/> No open questions <input type="checkbox"/> One question at a time <input type="checkbox"/> Be specific, not vague <input type="checkbox"/> Keep messages short and simple <input type="checkbox"/> Using gestures and pictures <input type="checkbox"/> Other _____	

Blue Access Needs Card

Side 1: Communication



The Blue Access Needs Communication Card lets you tell people how you like to communicate

You can let people know:

- ▶ If you have a **Support Plan** ⁺ that will help them support you better
- ▶ If you have a **Consistent Approaches Plan** ⁺
- ▶ If you have a **Behaviour Support Plan** ⁺

To help you communicate with others, you can tell people:

- ▶ How you like to communicate and talk
- ▶ If there are other ways you like to tell people things
- ▶ If you need an interpreter

To help others to communicate with you, you can let them know:

- ▶ If you like questions that you can answer with 'Yes' or 'No'
- ▶ If you like one question at a time
- ▶ If you like specific questions
- ▶ If you like information short and simple
- ▶ If you like pictures and gestures

To help make sure that you and the healthcare professional understand each other

You can decide

- ▶ How to let others know that you understand
- ▶ How others can let you know that they understand
- ▶ How to know that you agree to any plans about your health

There is also space for you to let them know anything else about how you communicate.

ACCESS NEEDS - COMMUNICATION SELF ADVOCACY IN HEALTHCARE	
Important information <input type="checkbox"/> I have a Support Plan or Consistent Approaches Plan <input type="checkbox"/> I have a Behaviour Support Plan	
1. How I communicate face to face Main communication method eg. touch and sign _____ _____ Back up communication method eg. Written _____ _____	4. Confirmation of understanding How you will know I have understood eg. thumbs up when I understand _____ _____ How I will know you have understood me eg. thumbs up when you understand _____ _____
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Blue Access Needs Card

Side 2: Environmental / Sensory

This side of the card allows you to explain what kind of environmental and sensory access needs you have.

It is broken up into the following sections:

A table of sensory/environmental access needs: Your specific sensory needs, that when met will increase your ability to access the space safely, as well as communicate effectively during the appointment itself - rather than spend cognitive resources coping with an overwhelming environment.

Location checkboxes: What locations you prefer/need to be near, this could be: close to an exit, close to the bathroom, and a space for other needs.

Personal Solutions to help with your environment:

A personal checklist and plan to help alleviate some environmental barriers that can not be fixed, and allows for some self advocacy in situations. This can include wearing sunglasses inside, using a hoodie or ball cap to prevent bright lights from hurting eyes, and bringing a jumper when it might be cold.

How healthcare providers can help with this: What healthcare workers can do to help maintain a comfortable environment for you. This can include turning off noisy machines, keeping a moderate temperature, and dimming lights.

Autistic people often experience heightened senses, which can make places like waiting rooms difficult to be in.



Some examples for administration teams on what could be helpful to autistic people:

- ▶ Have particular times that are low sensory for example 10am to 11am
- ▶ Have a social script of what we will experience at the clinic/hospital
- ▶ Have photos of the waiting room available on your website and brochures
- ▶ Ensure that you don't have multiple sources of sound, especially when there is an expectation to listen for your name to be called
- ▶ Reduce the amount of signage where possible as too much information can be overwhelming and confusing for people with cognitive disability

ACCESS NEEDS - SENSORY & ENVIRONMENTAL
SELF ADVOCACY IN HEALTHCARE

1. My sensory / environmental access needs are

SENSORY/ ENVIRONMENTAL eg. lighting	ACCESS NEED eg. no fluorescent bulbs, natural light is OK, no dim light
Lighting	
Sounds	
Temperature	
Touch	
Smell / scent	
Mobility	
Crowds / no. of people	
Time	
Seating	
Other	

Location

Close to exit

Close to bathroom

Other

2. My personal solution to help in physical environments
eg. headphones, sunglasses

3. How healthcare providers can help in physical environments
eg. dimming lights, turn off air conditioning

Blue Access Needs Card

Side 2: Environmental / Sensory

The Blue Access Needs Environmental Card lets you tell people what you need to be in a room or space.

You can let people know:

- ▶ If you like bright lights or not
- ▶ If you like things quiet or loud
- ▶ If you like things to be cool or warm
- ▶ If you don't like things that feel yuk
- ▶ If you don't like it when things smell strong
- ▶ If you use a wheelchair, walker, or a cane
- ▶ If you don't like it when there are lots of people
- ▶ If you like things to be on time
- ▶ If you need a seat

You can also let people know:

- ▶ If you like to be close to the exit
- ▶ If you like to be close to the bathroom

You can write or draw what helps you to be in a room or space. This could be wearing your sunglasses inside or wearing headphones.

You can also let other people know what they can do to make a room better for you.

ACCESS NEEDS - SENSORY & ENVIRONMENTAL
SELF ADVOCACY IN HEALTHCARE

1. My sensory / environmental access needs are

SENSORY/ ENVIRONMENTAL eg. lighting	ACCESS NEED eg. no fluorescent bulbs, natural light is OK, no dim light
Lighting	
Sounds	
Temperature	
Touch	
Smell / scent	
Mobility	
Crowds / no. of people	
Time	
Seating	
Other	

Location

Close to exit

Close to bathroom

Other

2. My personal solution to help in physical environments
eg. headphones, sunglasses

3. How healthcare providers can help in physical environments
eg. dimming lights, turn off air conditioning

Purple Professional Card



Side 1: Physical Procedures

This side of the card allows you to explain what your needs are during physical procedures.

Knowing what information is needed for consent and what the expectations are, you can be prepared for what happens during physical procedures and reduce anxiety.

It is broken up into the following sections:

How to ensure informed consent¹¹+: What information you might need to weigh up the benefits and risks of a physical procedure, as individuals we have different needs that can include cost, recovery time, and pain threshold.

Plan for how I will maintain consent during physical procedures: For specific communication around what you want to happen during a procedure, like when it should start, stop, slow down, or continue.

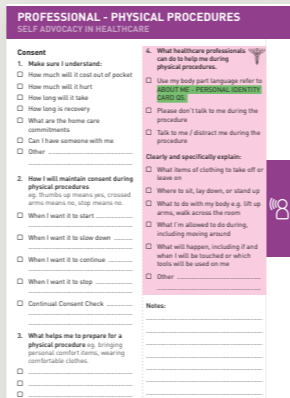
Continual consent⁺ option: If you would like to have consent continually checked in during the procedure; there is also a space for how often to check, plan on maintaining consent, how you would appear if something is wrong, and how you would appear if things are fine.

What helps me to prepare for a physical procedure: Personal checklist of items that can be used to help you prepare for a physical procedure. This can include physical items that help with anxiety like stim and fidget toys, as well as access tools like headphones and sunglasses.

What I would like healthcare professionals to do during a physical procedure: What you expect of doctors during physical procedures, such as:

- ▶ Using your personal body part language
- ▶ Talking/not talking during the procedure
- ▶ Explaining the procedure clearly so that you understand what expectations are for you. For example:
 - ▶ What to do with your body
 - ▶ What items of clothing to take off
 - ▶ If tools or touch will be used during the procedure and when that will occur.

Autistic people can experience discomfort during physical procedures, their experiences of pain can vary to that of allistic individuals¹². Being able to have autonomy over what is done to their bodies is an important part of self advocacy.



Purple Professional Card



Side 1: Physical Procedures

The Purple Professional Physical Procedures Card lets you tell people what you need to happen for you to agree to an appointment where you need to be touched.

You have the right to choose when and how someone touches you.

Sometimes during health appointments a doctor might need to touch you to help you.

It is important that others know what you agree to for a procedure that involves being touched.

You have the right to ask about and make sure:

- ▶ You have enough money for the procedure
- ▶ You know if it will hurt, and what it might feel like
- ▶ You know how long it would be until it is over
- ▶ You know how long it will take until you feel better
- ▶ You know what you would need to do at home after
- ▶ You know who you can have with you

Before you agree to a procedure you and the doctor or dentist can decide what you will do to let them know

- ▶ When you want it to start
- ▶ If you want it to slow down
- ▶ If you want it to continue
- ▶ When they need to stop

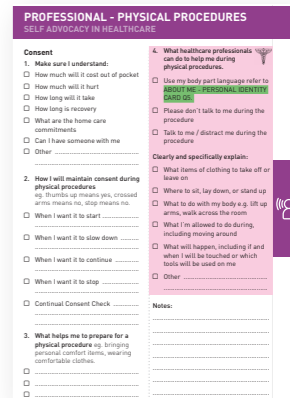
You can let them know that they need to check with you while it is happening.

You decide how often that can be and how they will make sure that you still agree.

You can also let them know how to tell if you are ok and how to tell if you are not.

There is also space for you to make a list of things that help you before you have a procedure, this can be like...

- ▶ Wearing comfortable clothing
- ▶ Bringing along a favourite toy
- ▶ Having someone with you



Purple Professional Card



Side 2: Pain

This card helps you to explore what your normal experiences of pain look like, feel like, and to help you describe pain in a way that healthcare workers can use.

Autistic individuals can display and experience pain differently than allistic folk, and have difficulty in describing pain in a way that helps in symptom exploration.12-14

It is broken up into the following sections:

Today my pain: Here you can indicate your current pain as either:

1) Moderate or Low Pain

2) High Pain

3) Extreme Pain

How I appear and act on a bad pain day: What it looks like when you are in a lot of pain.

How I appear and act on a good pain day: What it looks like when you are in a minimal amount of pain.

How I communicate that I am in pain: Your communication plan for if you are in pain. This is important for individuals who might become non-speaking / non-verbal when they are in pain.

My pain profile: For you to indicate what kind of pain you experience, this can include constant or varied pain, and pain sensitivity that changes regularly.

How the healthcare professional needs me to describe my pain: For healthcare workers to narrow down the scope of what specific information they need in relation to your pain.

What pain measurement tools are helpful to me: What kind of pain scales and lines of questioning help you to communicate your pain in a way that is understood.

An autistic person's communication style can change when they are in pain. For example, autistic people sometimes become non-speaking / non-verbal when under pressure or overwhelmed. It is good to know in advance what a person's needs are during these moments.



Self advocacy for autistic individuals includes deciding how they will continue with communication when verbal communication is not an option.

Question 5 of the Pain side of the Purple Professional Card allows the healthcare professional to clearly communicate what information they need. This is because vague and open questions about pain can yield incorrect responses that leave autistic individuals vulnerable and without appropriate care.

Purple Professional Card



Side 2: Pain

The Purple Professional Pain Card lets you tell people what it is like for you when you are in pain.

Everyone feels pain differently. Sometimes the way people act and look when they are in pain is not how others act and look. Sometimes when people are in pain, they have a hard time letting people know.

To help others understand you, you can use this card to tell people:

- ▶ How you look and act when you are in a lot of pain
- ▶ How you look and act when you are in a little bit of pain
- ▶ If you have pain all the time
- ▶ If you have pain some of the time
- ▶ If you feel the same pain differently on different days

There are different ways that people can find out how much pain you are in. You can choose what tools help you to tell others about your pain.

Bring this card with you when you go to see your healthcare professional. If you are in pain on the day, show the professional this card. There is a place for you to point to let them know if:



1. You are in a little bit of pain



2. You have a medium amount of pain



3. You are in a lot of pain

There is also space for you to let them know anything else about what you need when you are in pain.

Red Emergency Card

Side 1: Crisis and Self awareness

Oftentimes during a crisis some autistic people become non-speaking / non-verbal, are unable to process communications, or generally be in a state where they are only able to manage themselves and not the needs of others. This side of the card is designed to help you and supporters to explore how you experience a crisis so that others can know what to do for you in advance, to ensure you are treated with dignity and respect.

It is broken up into the following sections:

How I appear when I'm having a good moment / day: What you look like when you are doing ok. This can help healthcare workers and others to know that when you appear this way, and/or use these actions or words that you are in a better state of mind and body.

How I appear when I'm having a bad moment / day: What you look like when you are NOT doing ok. This can help healthcare workers and others to know that when you appear this way, and/or use these actions or words that you are in a poorer state of mind and body.

What to do if I'm having a meltdown or appear agitated/distressed: What your needs are during a meltdown.

What to do if I'm having a shutdown or appear unresponsive: What your needs are during a shutdown.

How to help me figure out what I am experiencing (Self Perception): For you to explore what is happening in your body and mind. Autistic Individuals often experience different internal senses. Being able to explore what is normal or not in bodily function can be helpful in determining if something is wrong.

How to help me describe what I am experiencing (Self Description): For you to explore what words to use to explain emotions, body feelings, and physical experiences that can help healthcare workers to understand what is happening to you.

Anxiety and Panic: What it looks like when you are

experiencing anxiety and panic, this lets others know in advance what they can do to assist during these moments.

What I need people to tell me: What information that you would like to be explicitly told by healthcare workers. This could include what emotions the healthcare worker is experiencing, and when to leave the appointment.

Additional things healthcare professionals should know:



Some autistic folk have trouble within social contexts and can have **emotional agnosia**. Having the healthcare worker let them know what they are feeling helps reduce the anxiety that can occur from not knowing.

Autistic people experience higher levels of anxiety and stress¹⁵, this contributes to experiences of overload and crisis which can be shown as **Meltdowns** or **Shutdowns**.

During these moments, an autistic person might be at risk of harm to others or themselves, it is important to know that these experiences are as distressing for the person as well as others around them.

Meltdowns and **Shutdowns** are natural physical responses to situations and stimuli that are overwhelming to an autistic person. They serve to let the person and others around them know that something is wrong and function as self-defense mechanisms. Both of these experiences are important parts of an autistic person's way of life and coping with the world.

Co-occurrence of Alexithymia is common with autistic individuals. **Alexithymia** is a condition that can prevent individuals from being able to accurately know and explain their emotional response (which can include pain)^{15,16}.

Red Emergency Card



Side 1: Crisis and Self awareness

The Red Emergency Crisis and Self Awareness Card lets you tell people what happens to you when there is an emergency.

Everyone has good days and bad days. People can have bad days for no reason, or because something bad happens. People often get upset on bad days.

To help other people know what helps you when you are upset, you need to let them know some things about you before it happens.

You can help others understand you by letting them know:

- ▶ How you look when you are having a good day
- ▶ How you look when you are having a bad day
- ▶ What others can do if you are having a **meltdown**  or look upset
- ▶ What others can do if you are having a **shutdown**  or stop responding

Some people have a hard time knowing what they are feeling. Other people can help by:

- ▶ Asking you questions
- ▶ Finding out what your body is doing

Some people have a hard time knowing what words to use for feelings. You can use tools to help you find the right words like:

- ▶ Having examples
- ▶ Having people explain what the words mean

Some people experience anxiety or panic. You can help others by letting them know:

- ▶ What you look like when you have anxiety or panic
- ▶ What you need other people to do

Sometimes we need others to tell us what they are feeling. You can ask people to tell you

- ▶ What they are feeling
- ▶ When it is time to leave

EMERGENCY - CRISIS AND SELF AWARENESS
SELF-ADVOCACY IN HEALTHCARE

- How I appear when I'm having a good moment/day eg. when I am happy I am talkative
- How I appear when I'm having a bad moment/day eg. when I am anxious or distressed I am quiet
- What to do if I'm having a meltdown or appear agitated/distressed eg. wait for it to pass then talk to me
- What to do if I'm having a shutdown or appear unresponsive eg. help me get home, switch to writing
- How to help me figure out what I am experiencing (self-perception) eg. probing questions, body scan
- How to help me describe what I am experiencing (self-description) eg. examples and definitions of words, emotion wheel

Anxiety and panic
When I experience anxiety or panic I appear like this _____

During moments of anxiety and/or panic my needs are _____

What I need people to tell me

What emotions the healthcare person is experiencing

When to leave

Other _____

Red Emergency Card

Side 2: Medication and Allergies

This side of the card allows you to explain how you experience medications and if you have any allergies, intolerances or other barriers to taking medications. It is broken up into the following sections:

Where to find my list of medications: Where you keep a list of your medications. Some individuals who have coexisting chronic illness or conditions that include medication as a treatment might have a long list of what they are currently taking.

Allergies: What allergies you have.

Sensitivities and intolerances: What sensitivities and intolerances you have.

Barriers to accessing medication: Any issues in the way that medication is prescribed or delivered to you. This can include physical inability to take pills like dysphagia (problems swallowing), financial barriers, memory issues, and allergies. By selecting any or all of these boxes you can tailor a medication plan to help you to advocate for your needs in getting medication that works for you.

Preferred method of medication dispensing: What is the best way to give you medication. This can be helpful for people who have memory problems, or anxiety about needles.

Four parts that allow you and the healthcare worker to make a collaborative plan for your medication:

- ▶ Plan for if the medication is too strong
- ▶ Plan for if the medication is too weak
- ▶ Plan for starting medication - This can include slow dose increase so that physiological response can be monitored.
- ▶ Plan for stopping medication - Some drug withdrawal symptoms can be challenging even if the dose is low compared to the average use.

- ▶ Home Care - What kind of home care commitment information you need to ensure that your medication use is safe and effective. This could include written information, Reminders, Medication Plan.

Other Important Information: What treatments need to occur concurrently with medication to ensure your informed consent. This can include

- ▶ Providing written information about possible side effects and withdrawal symptoms
- ▶ Ensuring that you get blood tests when required and asked for.

This is important as some medications can have other effects on the body that need to be monitored, being able to self advocate for this is important.

There are often co-occurring experiences of food sensitivities, and allergies with autistic people which can interfere with medication, it is important to acknowledge this when making a treatment plan that includes oral medication and some inhalers.^{17,18}



Most prescription medications use fillers for their products such as lactose, dairy, and gluten which if not notified about can be fatal to some individuals, or make them sick and impact their quality of life if given.

Additionally, there can often be co-occurring experiences of dysphagia within the autistic population¹⁹, understanding the impact of this on treatment is essential in person centred care.

Red Emergency Card

Side 2: Medication and Allergies

The Red Emergency Medication and Allergies Card lets you tell people what happens to you when you take medications.

Some people use medication.

It is important to tell people what medication you are taking.

It can help other people if you have a list of:

- ▶ What medication you take
- ▶ How much of the medication you take
- ▶ What time of day you take medication
- ▶ If you use natural medicines and herbs
- ▶ If you drink
- ▶ If you use drugs

Some people have allergies. It is important to tell people if you have any allergies.

Some people get sick from some food and colours It can help others to know if some things make you sick.

Some people have trouble being able to take some types of medicine. You can let people know:

- ▶ If you have problems with swallowing
- ▶ If you have memory problems

- ▶ If you do not have money to pay for medicine
- ▶ If you have allergies or get sick from things in pills

You can take most medicine in different ways. For example, some medicines come in powder, a pill, a capsule, or a liquid. You can ask your healthcare professional for the type of medicine that is best for you.

If you are going to start taking a new medication you can make a plan with your doctor.

A medication plan can help you:

- ▶ Know what to do before you start the medication
- ▶ Learn about side effects
- ▶ Work out what to do if the medication is too strong
- ▶ Work out what to do if the medication is too weak
- ▶ Know how to stop taking the medication
- ▶ Learn what you need to do at home

EMERGENCY - MEDICATION AND ALLERGIES
SELF-ADVOCACY IN HEALTHCARE

- Where to find my list of medications
- My allergies
- My sensitivities and intolerances
- Barriers to accessing medication
 - I have problems with swallowing
 - Memory problems
 - Financial
 - Allergies / intolerances to ingredients
 - Other _____
- Preferred method of medication dispense eg. Pills because needle phobia, no pills due to memory, reminders if about to run out
- Plan for if the medication is too strong
- Plan for if the medication is too weak
- Plan for starting medication
- Plan for stopping medication
- Home Care

Please provide me with:

 - Written instructions for home/ after care
 - SMS/Email reminders
 - Medication plan for start, stop, and monitor
 - Other _____
- Other important information

eg. provide me with side effect info, give me blood tests when asked

Please make sure that: _____

Orange How to Use Card

Side 1: For individuals and supporters

This side of the card is for you, as well as your carers, family members, advocates, and disability support professionals.

It outlines what the pack is for and how to use it.

There is a section that allows for you to point to who is accompanying you at a healthcare appointment or treatment, it includes:

- ▶ Carers

- ▶ Family Member

- ▶ Advocate

- ▶ Disability Support Professional

...and a space for you to write someone else.

You and a carer/supporter can fill out this card before attending appointments.

If you have an NDIS plan with core or capacity building funding, you can ask your NDIS support provider and support professionals to help you fill out this pack.

When you meet with doctors, dentists, other care workers, or healthcare administration staff, you can use the appropriate cards to share your support and healthcare needs. Not every card will be appropriate for every professional (e.g. Physical Procedures and Pain may not be relevant to administration staff).

It is up to you what information you write on the cards, and which card/s you hand over to each professional.

HOW TO USE - FOR YOU
SELF ADVOCACY IN HEALTHCARE

This card is for You, or your: Carer, Family Member, Advocate, Disability Support Professional

Who is with me today?



<input type="checkbox"/> Family Member	<input type="checkbox"/> Carer
<input type="checkbox"/> Advocate	<input type="checkbox"/> Disability Support Professional
<input type="checkbox"/>	

You and a carer/supporter can fill out this card before attending appointments.

If you have an NDIS plan with core or capacity building funding, you can ask your NDIS support provider and support professionals to help you fill out this pack.

When you meet with doctors, dentists, other care workers, or healthcare administration staff, you can use the appropriate cards to share your support and healthcare needs. Not every card will be appropriate for every professional (e.g. physical procedures and pain may not be relevant to administration staff).

It is up to you what information you write on the cards, and which card/s you hand over to each professional.

See the book *Self Advocacy in Healthcare* to learn more about how to use these cards.

Orange How to Use Card

Side 1: For individuals and supporters

The first side of the Orange How to Use Card is for you and your supporters to help you and others learn about the coloured cards.

You can let others know who is with you by pointing to one of these:

- ▶ Carer

- ▶ Family Member

- ▶ Advocate

- ▶ Disability Support Professional

- ▶ Someone else

You and a carer/supporter can fill out this card before you go to your appointment.

If you have an NDIS plan with core or capacity building funding, you can ask your NDIS support provider and support professionals to help you fill out this pack.

When you meet with doctors, dentists, other professionals, or healthcare office workers, you can choose to show them your cards.

Some people don't need to see all of the cards. It is up to you who you share your cards with.

It is up to you what information you write on the cards, and which card/s you hand over to each professional.

HOW TO USE - FOR YOU
SELF ADVOCACY IN HEALTHCARE

This card is for You, or your: Carer, Family Member, Advocate, Disability Support Professional

Who is with me today?



<input type="checkbox"/> Family Member	<input type="checkbox"/> Carer
<input type="checkbox"/> Advocate	<input type="checkbox"/> Disability Support Professional
<input type="checkbox"/>	

You and a carer/supporter can fill out this card before attending appointments.

If you have an NDIS plan with core or capacity building funding, you can ask your NDIS support provider and support professionals to help you fill out this pack.

When you meet with doctors, dentists, other care workers, or healthcare administration staff, you can use the appropriate cards to share your support and healthcare needs. Not every card will be appropriate for every professional (e.g. physical procedures and pain may not be relevant to administration staff).

It is up to you what information you write on the cards, and which card/s you hand over to each professional.

See the book *Self Advocacy in Healthcare* to learn more about how to use these cards.

Orange How to Use Card

Side 2: For professionals

This side of the card is for healthcare professionals including: Doctors, Dentists, Allied Health Professionals, and healthcare Administration Staff.

The card lets the professionals know what the pack is for and how to use it.

It introduces the healthcare workers to this symbol that lets them know that a section in the cards or this book is meant for them.



It lets them know that the cards and this book are tools to help them to build a healthy working relationship with you.

It also outlines that it is your choice to share all of the cards, some of the cards or none of the cards with them.

Please read the cards your client chooses to provide to you, and communicate any questions and concerns to your client and/or their supporters in their preferred communication method.


There is a space on the front packet of the kit for a professional to stamp, date, and sign this kit to help authenticate its use.

HOW TO USE - FOR HEALTHCARE WORKERS
SELF ADVOCACY IN HEALTHCARE

This card is for Doctors, Dentists, Allied Health Professionals, and Healthcare Administration Staff.

These cards have been created to help people communicate their support needs and experiences with health care professionals.

When you see this symbol it indicates a section that is for the doctor / healthcare professional / administrator / first responder.





These cards have been filled in by your client and their supporters to help you build a healthy working relationship with them.

Your client may show you all of their cards or some of their cards with information they want to share with you.

Please read the cards your client chooses to provide to you, and communicate any questions and concerns to your client and/or their supporters in their preferred communication method.

There is a space on the front packet of the kit for a professional to stamp, date, and sign this kit to help authenticate its use.

See the book *Self Advocacy in Healthcare* to learn more about how to use these cards. The book also contains information about for healthcare professionals

Orange How to Use Card

Side 2: For professionals

The second side of the Orange How To Use Card is for doctors and health professionals to read to let them know about the cards and how they work.

Healthcare Workers could be

- ▶ Doctors
- ▶ Dentists
- ▶ Nurses
- ▶ Occupational Therapists
- ▶ Physiotherapists
- ▶ Speech Pathologists
- ▶ Counsellor, Psychologist, or Psychiatrist
- ▶ Healthcare Office/Reception staff

The card tells healthcare workers about this image.

If they see this image, it means that there is information for them on the card.

The card helps healthcare professionals learn that they need to work with you in a healthy working relationship and that they need to listen to you.

It is your choice to show your cards to people. You might show your doctor:

- ▶ All of the cards
- ▶ Some of the cards
- ▶ None of the cards

It is up to you what to share.


You can get your doctor to write their name on the front and put a stamp on it if you like. This might help other healthcare professionals understand how important your needs are to your healthcare.

HOW TO USE - FOR HEALTHCARE WORKERS
SELF ADVOCACY IN HEALTHCARE

This card is for Doctors, Dentists, Allied Health Professionals, and Healthcare Administration Staff.

These cards have been created to help people communicate their support needs and experiences with health care professionals.

When you see this symbol it indicates a section that is for the doctor / healthcare professional / administrator / first responder.





These cards have been filled in by your client and their supporters to help you build a healthy working relationship with them.

Your client may show you all of their cards or some of their cards with information they want to share with you.

Please read the cards your client chooses to provide to you, and communicate any questions and concerns to your client and/or their supporters in their preferred communication method.

There is a space on the front packet of the kit for a professional to stamp, date, and sign this kit to help authenticate its use.

See the book *Self Advocacy in Healthcare* to learn more about how to use these cards. The book also contains information about for healthcare professionals

Rights and Responsibilities

Under the Australian Charter of Healthcare Rights everyone has seven key rights in all Australian healthcare²⁰:

Access

- ▶ Healthcare services and treatment that meets their needs

Safety

- ▶ Receive safe and high quality health care that meets national standards
- ▶ Be cared for in an environment that is safe and makes them feel safe

Respect

- ▶ Be treated as an individual, and with dignity and respect
- ▶ Have their culture, identity, beliefs and choices recognised and respected

Partnership

- ▶ Ask questions and be involved in open and honest communication
- ▶ Make decisions with their healthcare provider, to the extent that they choose and are able to include the people that they want in planning and decision-making

Information

- ▶ Clear information about their condition, the possible benefits and risks of different tests and treatments, so they can give their informed consent
- ▶ Receive information about services, waiting times and costs
- ▶ Be given assistance, when they need it, to help them to understand and use health information
- ▶ Access their health information
- ▶ Be told if something has gone wrong during their health care, how it happened, how it may affect them and what is being done to make care safe

Privacy

- ▶ Have their personal privacy respected
- ▶ Have information about them and their health kept secure and confidential
- ▶ Give feedback
- ▶ Provide feedback or make a complaint without it affecting the way that they are treated
- ▶ Have their concerns addressed in a transparent and timely way
- ▶ Share their experience and participate to improve the quality of care and health services

Complaints

Everyone has the right to make a complaint about a health service provider if that provider has:

- ▶ failed to provide satisfactory care
- ▶ failed to provide enough information or denied the patient their right to choose
- ▶ denied the patient respect, dignity or privacy, or
- ▶ been negligent or unprofessional.

State Government departments of Health and Human Services

In Victoria, you can contact the Department of Health and Human Services using the advice on this webpage:

<https://www2.health.vic.gov.au/about/participation-and-communication/making-a-complaint>

To contact the Victorian Health Complaints Commissioner directly, call 1300 582 113 or visit:

<https://hcc.vic.gov.au/make-complaint>

Australian Health Practitioner Regulation Agency (AHPRA) is the national organisation responsible for looking after the registration of: Aboriginal and Torres Strait Islander Health Practitioners, Chinese Medicine Practitioners, Chiropractors, Dentists and Oral Health Professionals, Doctors, Medical Radiation Practitioners, Nurses and Midwives, Occupational Therapists, Optometrists, Osteopaths, Paramedics, Pharmacists, Physiotherapists, Podiatrists, Psychologists.

If you have a concern about a professional, visit this webpage and follow the instructions. You can ask a supporter to help you if you need.

<https://www.ahpra.gov.au/Notifications/Raise-a-concern.aspx>

Other Resources

ASAN - Resources for Autistic people:

<https://autisticadvocacy.org/resources/>

Australian GLBTIQ Multicultural Council - LGBTIQ Multicultural Resources:

<https://www.agmc.org.au/resources-support/>

Autism and Race - Resources by/for autistic People of Colour:

<https://autismandrace.com/resources/>

Bisexual Alliance Victoria - Information for professionals on working with multigender attracted people:

http://www.bi-alliance.org/?page_id=1107

Dysphagia for people with Autism and Learning Disabilities - Resource Sheet:

<https://www.optionsautism.co.uk/wp-content/uploads/2017/11/Options-Dysphagia-Help-Sheet-Issue-11.pdf>

Genderqueer Australia - Resources for medical practitioners, researchers, genderqueer and trans people:

<https://www.genderqueer.org.au/resources/>

Inclusion Melbourne - Inclusion Designlab citizenship and inclusion guides:

www.inclusiondesignlab.org.au

Intersex Human Rights Australia - Resources:

<https://ihra.org.au/category/policy/resources/>

Self Advocacy Resource Unit (SARU) - Disability Self Advocacy Resources:

<http://www.saru.net.au/Resources>

Transgender Victoria - Information for Trans people:

<https://transgendervictoria.com/information/for-trans-people>

Voices Together - Australian Self Advocacy Resources:

<https://www.voicestogether.com.au/self-advocates/toolkits-resources-how-to/resources/>

Advocates and advocacy services

ASAN: Autistic Self Advocacy Network

www.autisticadvocacy.org

Autistic Self Advocacy Network of Australia and New Zealand (ASAN AUNZ)

<http://www.asan-au.org/>

Black Rainbow: Aboriginal and Torres Strait Islander LGBTIQI Advocacy

<http://www.blackrainbow.org.au/>

Rainbow Rights and Advocacy: LGBTIQ+ people with intellectual disability

www.saru.net.au/Groups/Rainbow-Rights

VMIAC: Victorian Mental Illness Awareness Council

www.vmiac.org.au

DARU: Disability Advocacy Resource Unit

www.daru.org.au

Rainbow Rights: LGBTIQ+ Intellectual Disability Advocacy Group

<https://www.voicestogether.com.au/self-advocates/find-group/vic/rainbow-rights-and-advocacy-group/>

YDAS: Youth Disability Advocacy Service

www.yacvic.org.au

+ Glossary

Administrative Identity - How you want to be known in writing, this could be on letters, in emails, and text messages.

Alexithymia - When a person is unable to identify or describe their feelings.

Allistic - Someone who is not autistic

Autistic / Autism Spectrum - a neurological variation that occurs in 1% of people, often classified as a developmental disability.

Behaviour Support Plan (BSP) - A document developed by an NDIS registered provider of Specialist Behaviour Support. BSPs sometimes include clear directions for the use of restrictive practices (mechanical, physical, chemical, seclusion, and environmental). BSPs must be approved by the NDIS Quality and Safeguards Commission and their implementation must be monitored by the key support providers in the person's life.

Body Dysphoria, Body Dysmorphia - When people feel upset by their body.

Co-occurring, Co-occurrence - When you have sets of symptoms or conditions that often go together.

Consistent Approaches Plan - A document used by some support organisations to ensure the needs and choices of the people they support are effectively communicated to new people they meet.

Continual Consent - Making sure that you still agree with something while it is happening, by being checked in with regularly.

Dyscalculia - When you have a hard time with maths and numbers.

Dyslexia - When you have a hard time with reading and letters.

Dysphagia - Difficulty in swallowing, this can also include sucking, drinking, chewing, eating, or when food and drink goes down the wrong way. People who have dysphagia often cough when they try to swallow things.

Dyspraxia - When your body has a hard time connecting movements and doing tasks or movements in order.

Delayed Echolalia - Repetition of words and sounds when they are heard but from a later time. Like a delayed echo.

Echolalia - Repetition of sounds when they are heard, like an echo.

Echopraxia - Repetition of movements when they are seen, like a physical echo.

Emotional Agnosia, Social-Emotional Agnosia or Expressive Agnosia - When a person is unable to identify the emotions of other people.

Gender Dysphoria - When a person feels distress about the way their body and gender fit together.

Informed Consent - When a person gives their full permission for something to happen, because they know what the risks and benefits are.

Low Sensory - An environment that has reduced sensory input, this can mean that lights are dimmed, noises are removed, and temperatures not hot or cold.

Meltdown - A body response to overload and over stimulation, often when there is a lot of sensory stuff to process like lights, noise, smell, and temperature. It can be physical or verbal and can look like crying, shouting, repeating movements, and aggression.

Neurodiverse - The idea that having brains that function differently does not mean that they are wrong or broken.

Neurodivergent - Being someone who has a brain that functions differently, this can include being autistic.

Neurotypical - Being someone who has a brain that functions in a way that is not divergent, often used to describe people who are not autistic.

Private Identity - How you want to be talked about when you are in private with a healthcare worker, usually when you are alone with them or with people you trust.

Public Identity - How you want to be talked about when you are in a public space like a waiting room.

Referral - When a healthcare professional sends you to another healthcare professional.

Shutdown - A body response to overload and over stimulation often after being around other people. A person who has shutdown might not be able to talk, move, or might leave a space without warning.

Side Effects - Additional things that happen to you, when you take medicine or get treatments they are often unexpected and unwanted.



Social Script - A tool used to explain what a person would usually experience in an environment or situation, this is usually a step by step outline of what would happen when you do something or go somewhere and can be helpful to prepare you.

Support Plan - For example, Active Support plans, administrative documents prepared by supported accommodation staff, or Support Plans prepared by support providers according to the NDIS Practice Standards.


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