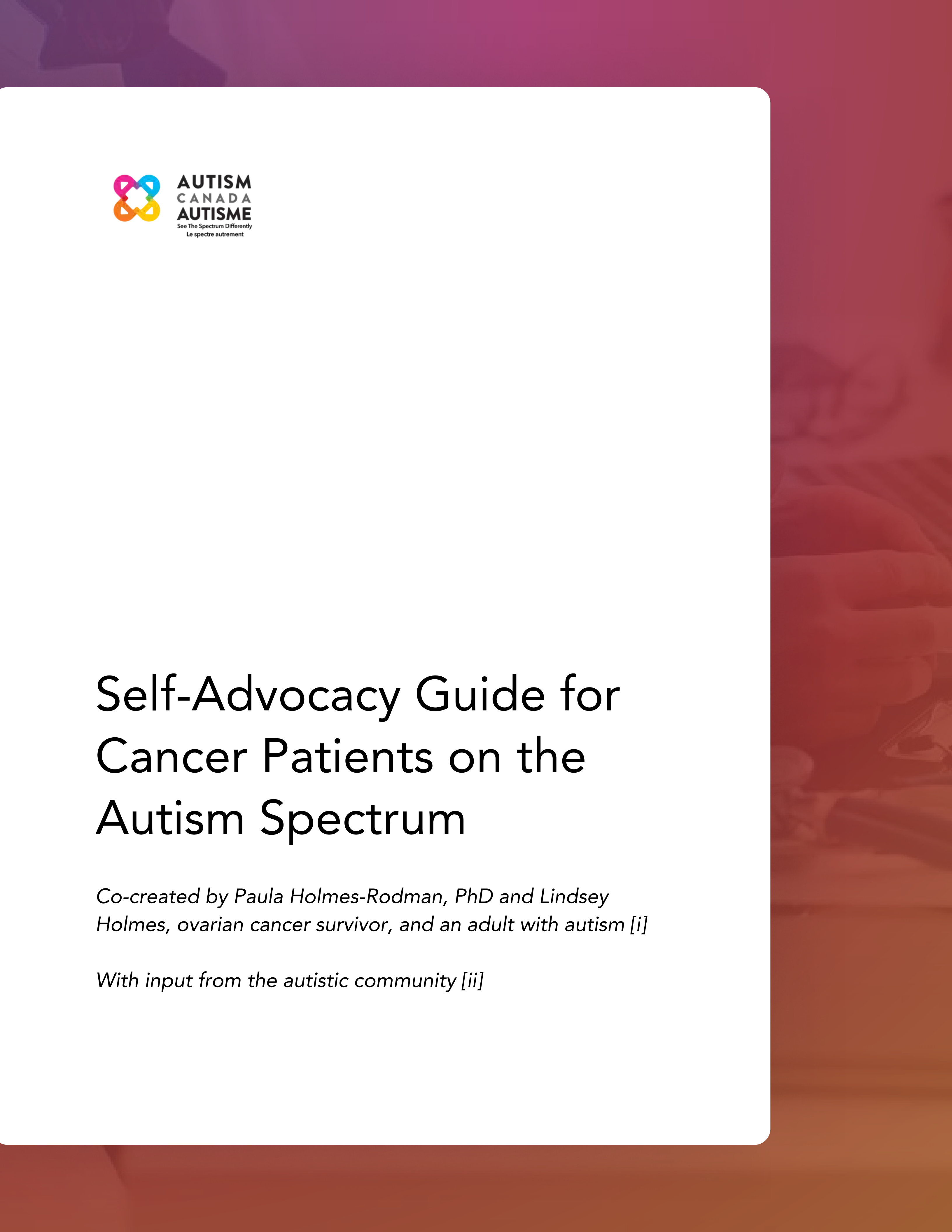

AUTISM
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Le spectre autrement

Self-Advocacy Guide for Cancer Patients on the Autism Spectrum

Co-created by Paula Holmes-Rodman, PhD and Lindsey Holmes, ovarian cancer survivor, and an adult with autism [i]

With input from the autistic community [ii]

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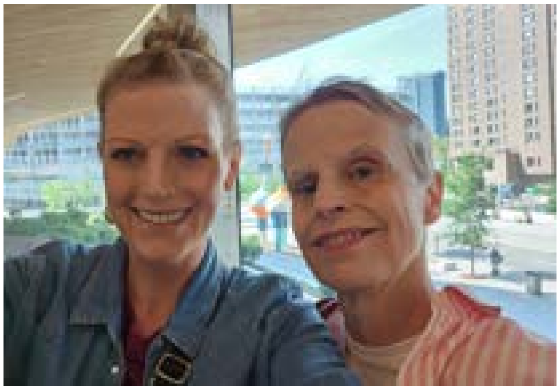
Dedication to Lindsey Holmes



This guide is dedicated to my sister, Lindsey Holmes, whose experience with ovarian cancer ended April 1, 2024. Lindsey was so proud of the work she and I did to create this guide and we are grateful for the input and assistance from Autism Canada and the many collaborators who made important contributions. We understand that this guide can't possibly cover every autistic person's experience with every cancer, but we hope it will be of some use to many of you.

I am so proud of Lindsey – as her cancer progressed, her sense of self became stronger, her voice became louder, and her desire to speak up for herself and for other autistic people grew. We called her last months her "butterfly days," and red was her favourite colour, so you'll see little red butterflies throughout this guide to remind you of my brave and beautiful sister and the transformation and growth she experienced. On her last night, she and I discussed our hopes for this guide, and that she was leaving this earth having contributed something of use to her community.

As Lindsey would say – "we wish you well on your journey."

With gratitude and hope,

Paula

Introduction

If you identify as autistic, or as a person with autism, or as someone on the autism spectrum, you might need some support with sensory or communication issues as you navigate cancer. We have assembled a patient self-advocacy guide that could help you and your support people think about how to:

Access the best healthcare possible
Have effective conversations with your healthcare team
Reduce your stress

You (together with a caregiver or support person, where appropriate) may want to print a copy of this guide, underline or circle what is most important to you, and share it with your healthcare team.

What do you want your healthcare team to know about you that they might not know from looking at your chart?

1 . Patient (You!)

a) How do you self-identify? How do you want others to refer to you? (e.g, person-first language, nickname, gender pronouns, etc.) e.g. “Please call me Lindsey. I am an adult with autism.” Or, “My name is Taylor, my pronouns are they/them. I’m autistic.”

b) What is important to you? What are your interests?

c) What do you like to talk about, think about, read about, watch or listen to?

d) What makes you happy? What is a great day for you?

1 . Patient (You!) - Continued

e) How do *you* define a good quality of life?

f) How have you successfully dealt with difficult or challenging times? What are your coping skills?

g) How do you express stress, anxiety or discomfort? What helps? What doesn’t?

2 . Place (The hospital or clinic)

a) Do you prefer a quiet space, or one with dim lights, to wait for your appointments or treatments? What if one is not available?

b) How do you respond to new environments? What helps? What doesn't?

2 . Place (The hospital or clinic)

c) How would you like to get to know your healthcare facility? Would an orientation appointment help? Consider this possibility prior to your surgery, chemotherapy, or radiation, for example.

d) How can you make yourself more comfortable during appointments, in waiting rooms, during chemotherapy, radiation, or other treatments, scans, hospital stays, or emergency room visits? (See below for ideas for a "Comfort Go Bag")

3 . Personnel (Healthcare providers)

a) Who is on your healthcare team? Who are the players, and what are their roles?

b) Do the members of your healthcare team understand neurodiversity, autism and any other issues that are important to *your* care?

c) How would you like to get to know your healthcare providers? Is it possible to see the same providers consistently? What if you can’t?

3 . Personnel (Healthcare providers) - Continued

d) If you use alternative or augmentative communication (AAC) technology, do the members of your healthcare team understand how to communicate with an AAC user, or do they need training?

e) Do all members of your healthcare team speak a language in which you are fluent? If not, how can you access a translator?

f) Do you want to connect with a support group or a patient navigator, where available? Could they be available online or in person?

4 . Products and Platforms (How you communicate)

a) What are your preferred communication methods and tools? For example, do you prefer to communicate in person, on the phone or via email when making appointments, getting test results, describing symptoms, or following up after treatments? For example, if you have difficulty on the phone, will your healthcare team/clinic help you book appointments by another method?

b) If you use alternative or augmentative technology (AAC), do you have resources to teach your healthcare team how to best communicate with you?

c) How do you like to receive new information about diagnosis and treatments? Read a brochure or booklet? Explore trusted sources on the internet? See information presented in pictures? Watch a video? Have a conversation (or more than one)?

4 . Products and Platforms (How you communicate) - Continued

d) Do you want to audio record your appointments to help you remember what happened?

e) Do you want a trusted support person to take notes for you during an appointment? If so, how would you like to receive those notes, or have that information relayed to you after your appointment?

f) Do you want your healthcare team to give you written information, images or videos for you to look at again later?

4 . Products and Platforms
(How you communicate) - Continued

g) How can you tell your healthcare team how you are feeling? What words, images, lists, diagrams, pictures, charts, or scales might help you express your symptoms, concerns and experiences? For example, there are some pain scales that use numbers, some use pictures of faces in different colours and facial expressions. Do these work for you? If you find pain scales difficult to navigate or understand, can you devise another way to rate, rank, or express your pain? Also, you may receive a checklist of symptoms to keep track of after surgery or during a course of chemotherapy. How can this best be adapted to your abilities, experiences, and needs?

5 . Pace

a) Do you prefer plain language when discussing diagnosis and treatment options? Do you prefer metaphors and analogies, or direct descriptions of health-related topics?

b) When learning about your illness and making treatment decisions, do you like to know all the possibilities at once, or do you prefer to learn new information a little bit at a time and make decisions step by step?

c) Do you feel like you need longer appointments than you usually get to discuss your health concerns? How can you ask your healthcare team to schedule longer appointments?

5 . Pace - Continued

d) Do you need your healthcare team to connect via email or phone before or after appointments?

e) During your appointments, do you need your healthcare team to slow down or skip some parts?

f) How can you make these needs known? Can you practice, write, or record a script?

6 . Processing

a) What helps you understand, or process new ideas or information?

b) Do you have auditory issues with telephone appointments?

c) Do you require in-person appointments whenever possible?

6 . Processing - Continued

d) Does Zoom, or the telehealth services available in your area, work better or worse than a phone appointment for you?

e) Do you require a longer appointment time for certain (or all) appointments? How can you ask for this?

f) During your appointment/procedure/hospital stay, do you need your healthcare team to check in with your understanding about what the treatment plan is or what your options are? Sometimes this is called “teaching back.”

6 . Processing - Continued

g) How can you let your healthcare team know that you are in the process of understanding or communicating? (e.g. so that they do not misinterpret periods of quiet or minimal eye contact?)

h) Do you have a script or plan to ask your healthcare team to slow down or repeat information?

i) How can you ensure that there is enough time for you to ask questions? Could you write or record them in advance? After an appointment, could you write or record any questions or concerns for next time?

6 . Processing - Continued

j) How can you ensure that your opinions are heard?

k) How do you make important decisions? Do you prefer to take information home before making a decision? Would it be helpful to have a timeframe for decision making? (e.g. Will it affect my cancer if I think about my options for a few days, or weeks? Do I have time to talk this over with my family, or do I need to make a decision today?)

l) What if there are emergency/ “right now” decisions that need to be made? How can you prepare for this?

6 . Processing - Continued

m) How do you express your consent? Does anyone help or support you with decision-making or consent?

n) Is there someone who you do *not* want to help you with decision-making or consent?

o) Who can you contact (and how and when) if you have questions after your appointments or procedures?

6 . Processing - Continued

p) If something unplanned happens during your appointment or treatment – like a "miss" – what is the best way for your healthcare team to contact you after the appointment to ensure understanding, follow up with any questions or concerns, or try another way to relay information and options?

q) Do you want to access your blood work and/or test results via the computer? Do you need support accessing this service and/or understanding your results as represented on the computer?

7 . Physical and Sensory Supports

a) Do you require any physical supports or accommodations during your appointments, treatments, or hospital stays?

b) If you use AAC, do you have a letter or other method to make sure all members of your healthcare team know it must stay with you?

c) Are you especially sensitive to lights, sounds, smells, or touch? Do you use any technology or devices to support you with these sensitivities, such as noise reducing earphones or sunglasses?

7 . Physical and Sensory Supports - Continued

d) Do you express yourself physically with stimming? How can you tell your healthcare team about the ways you self-regulate?

e) Interoception: How have you experienced and expressed discomfort, pain, or distress in the past? Do you think you describe sensations differently than neurotypical people do? Do you ever struggle to articulate sensations?

f) If you have experienced trauma or assault, how can healthcare providers ensure that you feel safe and supported during your cancer treatment? How can you communicate that to a new provider?

7 . Physical and Sensory Supports - Continued

g) Cancer and its treatments can be uncomfortable and cause changes to our physical bodies. Do you have any concerns about how you might experience or express these changes?

h) If chemotherapy is part of your treatment plan, could you use some extra support around sensory issues such as changes in tastes and smells, hair loss, itching, and other sensations?

i) If you are shaving your head in anticipation of chemotherapy-related hair loss, shopping for a wig, or attending a Look Good Feel Better program for assistance in skin care and scalp care, how can you communicate your sensory needs to your program ambassador? Is there a script you could create? Could you go to an autism-informed, or autism-aware salon or spa?

8 . Preparation, planning and predictability

Many of us find safety and comfort in our routines, and these can be challenged in the course of cancer treatment.

a) How can your healthcare team help you with what to expect? You and your family or other support person can work together to let them know about your coping skills, and how you usually get ready for new experiences, especially potentially unpleasant ones.

b) Ask if your procedures can be adapted to manage pain or anxiety, if these are specific concerns for you. For example, do you want more time or a quieter place for an injection or a biopsy? E.g. for a Covid test, you may want to request a saliva test or throat swab instead of a nasal swab.

8 . Preparation, planning and predictability - Continued

c) Do you want to see new pieces of medical equipment, or learn about procedures before they happen? Would you like this to happen on the day of your procedure, or some time in advance? E.g. Would you like to see a scanner, or visit a chemotherapy room?

d) Do you want your healthcare team to ask permission before they touch you?

e) Do you want your healthcare team to let you know what will happen as your appointment or procedure progresses? (e.g. “First we will take your blood pressure, then we will start an IV…”)

8 . Preparation, planning and predictability - Continued

f) Consider making a toolkit/ “go bag”/backpack of comfort items to bring with you to treatments, appointments, hospital stays, or the emergency room, if necessary. See our list of suggestions on page 32.

g) What has brought you comfort in the past when your routines have been challenged and the unexpected has happened?

h) What else in your life might be disrupted as you navigate cancer? Can you pre-arrange meals, arrange to speak to your employer, consider speaking to a financial advisor, arrange for the care of children or pets?

8 . Preparation, planning and predictability - Continued

i) Can you connect with other members of your healthcare team if you have pre-existing or co-occurring conditions? For example, if you have a GP/family doctor who is helping you with epilepsy or panic attacks, can that doctor provide you with a note, or advice on how to make sure your oncology healthcare team knows what to do? Keep everyone in the loop! Don't assume that your healthcare providers talk to each other (sometimes they don't!)

9 . Proxies, or Support People

a) Does anyone help or support you on a daily or weekly basis?

b) Do you have who and what you need for at-home support, whether it's after surgery, during chemotherapy, radiation or other treatments?

c) Who will help monitor your health and ensure ongoing care at home?

9 . Proxies, or Support People - Continued

d) How will you and this support person(s) record/keep track/monitor your health, medication use and ongoing care while you are at home?

e) Can your support person(s) accompany you in-person for your surgery, treatments and appointments? If not, can they attend your appointments or treatments over speakerphone or virtually? How are you and your healthcare team going to facilitate their virtual attendance? (It's a good idea to sort this out in advance.)

f) What role will your proxies play during your appointments? How can you ensure that your healthcare team is speaking to *you*, and not your proxies, or support people?

9 . Proxies, or Support People - Continued

g) How have you made important or difficult decisions in the past? Who will help you do so in the future? Who do you not want to help you?

h) Would you like an opportunity to communicate privately to a member of your healthcare team, without your support person in the room/on the call?

10 . Patience

a) How can you ask your healthcare team to be patient with you? (For example, if you need a minute to catch up with them?)

b) How can you be patient with your healthcare team? (For example, if they need a minute to catch up with you?)

c) Most importantly - how can you be patient with yourself? What kinds of self-talk, or feedback can you use to make sure you're not being hard on yourself?

10 . Patience - Contiued

d) Cancer and its treatments can be overwhelming, disruptive and stressful. How can you do small things to take care of ALL of you? Do you find comfort in the favourite parts of your routine? Can you make sure you have time alone, if that's what you need, or with the people, pets, or places that bring you comfort and happiness?

Resources

Comfort Go Bag

Suggestions for building your own "Comfort Go Bag" for chemotherapy, procedures, appointment days, hospital stays, or emergency room visits:

- ☐ Your AAC devices.
- ☐ Cell phone or tablet – preloaded with favourite music, games, meditation apps, pictures that make you smile, or distracting movies or videos.
- ☐ Charging cords (extra long) with wall adapters or batteries/battery packs.
- ☐ Phone numbers of people who support you (or ways to contact them).
- ☐ A patient self-advocacy guide with all your questions and concerns written, pictured, or recorded in advance.
- ☐ Noise cancelling earphones, ear defenders, ear plugs.
- ☐ Fidgets, fidget spinner.
- ☐ Favourite stuffed animal.
- ☐ Sweater or shawl.
- ☐ Weighted blanket. Neck pillow.
- ☐ Picture of a loved one, pet, or a special place.
- ☐ Favourite snack (if allowed or wanted during your treatment). Water bottle.
- ☐ Eye mask. Sunglasses.
- ☐ Earphones for music, conversations or games.
- ☐ Games. Puzzles.
- ☐ Books. Magazines.
- ☐ Pen and paper.
- ☐ Colouring books and coloured pencils or markers.

Autism Canada has Sensory Support Kits available for purchase on their site. You could add your own item to their backpack as well.
https://autismcanada.org/resources/sensory-support-kits/

Resources

Helpful Resources on the Web

We hate to make you do the work. We know you are dealing with cancer, but we also want you to know that you are not alone. If and when the time is right, we hope there is some helpful information here for you and/or your support people.

https://autismandhealth.org/
This site offers simple healthcare checklists and worksheets to help you make appointments, follow up after a visit, and ask for specific accommodations. There are a few simple templates and worksheets for the patient, as well as some information for healthcare providers.

https://a4aontario.com/the-autistic-health-access-project/
The Autistic Health Access Project. Autistic-led patient experience presentations to Canadian clinics and medical schools:

https://thinkingautismguide.com/2020/07/autistic-with-cancer-six-tips-for.html Anne Borden writes about her experiences with breast cancer treatments as an autistic person, and the barriers to accessing accommodations she has encountered. She offers strategies that have worked for her and other neurodivergent patients with whom she spoke. She includes some helpful scripts.

https://ddprimarycare.surreyplace.ca/tools-2/general-health/about-my-health/
You may find the worksheets designed for patients "with intellectual or developmental disabilities" helpful. They are fillable and are a good starting point for getting you and your support people thinking about how to have better encounters with your healthcare team. They are not specific to cancer or its treatments. The site also offers guidance for your healthcare team to better understand decision making capacity.

Resources

Helpful Resources on the Web - Continued

http://ddprimarycare.surreyplace.ca/wp-content/uploads/2019/08/5.2-My-Healthcare-Visit.pdf

This is a fillable form for the patient and/or support person to use before, during, and after a healthcare visit. It is not specific to cancer or its treatments, and is primarily focused on those patients with intellectual disabilities.

https://autisticadvocacy.org/wp-content/uploads/2019/05/PADSA-best-practices-for-inclusion-of-AAC-users.pdf

This is a very basic information sheet about how to include people who use augmentative and alternative communication. It is not specifically related to healthcare, but does cover basic guidelines for inclusion. You might show this to a member of your healthcare team.

https://www.patientprovidercommunication.org/tools-and-resources/links-to-helpful-resources/

A link to non-cancer specific AAC communication tools.

https://noncompliantpodcast.com/2020/12/22/a-neurodivergent-guide-to-your-radiation-treatments/

This is a recorded and transcribed description of a first-person account of an autistic woman’s experience of radiation treatments.

https://www.lifelabs.com/patients/patient-centred-care/serving-patients-with-autism/#article-tab-6-4466-_bc

LifeLabs offers specific blood work appointments for patients with autism in a number of locations in BC, Ontario and Saskatchewan.

Resources

Helpful Resources on the Web - Continued

https://bmjopen.bmj.com/content/12/2/e056904.full
Dr. Mary Doherty and Dr. Sebastien Shaw present their research on barriers to healthcare that autistic patients face and how these contribute to known healthcare disparities. They suggest that by focusing on issues of communication, sensory processing and predictability, patients with autism can be better served.

https://www.magonlinelibrary.com/doi/full/10.12968/hmed.2023.0006
Drs. Doherty, McCowan and Shaw offer a framework for clinicians to best serve autistic patients based on the acronym of SPACE: Sensory needs, Predictability, Acceptance, Communication and Empathy.

https://oncodefi.org/en/booklets/
These are plain language and picture booklets explaining cancer screening and pathways for patients with intellectual disabilities. You can order them from France.

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8958737/
“Considering autistic patients in the era of telemedicine: the need for an adaptable, equitable, and compassionate approach.” This academic article written by three neurodivergent doctors explores some of the benefits and drawbacks of telemedicine. If you need to request a different kind of appointment, or a different length of appointment, this article may help you have those conversations with your healthcare team, and help you feel that you are not alone in your experiences or needs.

https://donnie.lgbt/2020/11/02/aac-phrases-for-medical-advocacy/
This person has created phrases for use with AAC specific to medical advocacy.

Resources

Helpful Resources on the Web - Continued

https://awnnetwork.org/wp-content/uploads/2020/10/Final-Version-Before-You-Go-Know-Your-Rights-Booklet.pdf

The Autistic Women & Nonbinary Network and the National LGBTQ Task Force offer this guide for trans autistic people called Before You Go: Know Your Rights & What to Expect at the Doctor and in the Hospital. This guide will help our trans and autistic community members know better what to expect when going to doctors or hospitals, understand rights and responsibilities, and strategize for safety planning, effective communication, accommodations. While written from an American perspective, many of the key issues are shared across borders.

https://aidecanada.ca/

This is a national hub of resources for people with autism and/ or intellectual disabilities, some of which are healthcare related. There are several resources for healthcare providers, educating them on how to be better doctors to neurodiverse patients. Some are specific to older patients, none are specific to cancer and its treatments. The three links below might be specifically helpful.

https://aidecanada.ca/resources/learn/crisis-response/healthcare-experiences-aging-maxine's-story

In this video, Maxine talks about her experiences in the healthcare system as someone who is autistic and has faced cancer.

https://aidecanada.ca/resources/learn/asd-id-core-knowledge/infosheet---advance-care-planning---pooranlaw

This is an introduction to Advance Care Planning – expressing your wishes for treatments in case of illness and or in anticipation of end of life.

Resources

Helpful Resources on the Web - Continued

https://aidecanada.ca/resources/learn/asd-id-core-knowledge/understanding-healthcare-challenges-of-adults-with-autism
This study might make you feel empowered to tell your healthcare team to "respect the way I need to communicate with you."

https://www.albertahealthservices.ca/assets/info/cca/if-cca-cancer-patient-navigators.pdf
Alberta Health Services has patient navigators for Indigenous patients, those who live in rural areas, and/or those who are AYA (adolescent and young adult). None are neurodivergent-specific.

http://www.phsa.ca/aboriginal-health-site/Documents/PHSA%20IPN%20Services%20Brochure%20Print-Friendly%20Version.pdf
Indigenous Patient Navigators are available through the Provincial Health Services Authority in BC, It is not a neurodivergent specific program.

https://www.verywellhealth.com/pain-scales-assessment-tools-4020329
For more ideas on diverse pain scales which you could adapt to best serve your needs, consider this article.

https://www.pcpld.org/links-and-resources/
The Palliative Care for People with Learning Disabilities Network brings together service providers, people with a learning disability and carers working for the benefit of individuals with learning disabilities who have palliative care needs. Our ethos is that people with a learning disability should receive the coordinated support needed in living their lives to the full, until the end of their life.

Resources

Helpful Resources on the Web - Continued

http://www.tuffrey-wijne.com/?page_id=90 Dr. Tuffrey-Wijne is a Professor of Intellectual Disability and Palliative Care. She has some resources and publications on her site here about breaking bad news to people with intellectual disabilities which might be useful. https://www.tcd.ie/tcaid/accessibleinformation/#main-content Trinity Centre for Ageing and Intellectual Disability (Ireland) has developed an accessible planning tool for people with an intellectual disability to help them plan ahead so that their wishes can be respected at the end of their life. It is a tool for people with an intellectual disability, their families and their carers to use as they pause to think about the future. It supports ongoing conversations and building knowledge, attitudes and confidence for everyone involved so that wishes and desires are realised.

https://www.autism.org.uk/advice-and-guidance/professional-practice/palliative-care Jill Ferguson, Services Manager with Scottish Autism, discusses why they developed a good practice resource guide on end of life care for autistic people. She also offers some advice on providing palliative care for autistic people.

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[i] These were Lindsey's chosen self-identifiers. We are well aware that some people prefer to be called "autistic," others, like Lindsey, chose to be addressed as a "person with autism." These are just two choices. There are others, and we respect them all. That's part of self advocacy (see Question 1.a)

[ii] This guide emerged from the experiences of Lindsey as a patient and Paula as a caregiver, turned advocate. Specifics for the guide were created from ethnographic interviews (Paula interviewing Lindsey), research, and input from other members of the autism community. We are grateful for their input, feedback, support, and collaboration. We especially want to thank Bruce Petherick and Derek Seabrooke for their careful consideration and thoughtful discussions of this guide.