

Guidance Notes for My Medical Alert Passport (MAP)

For Individuals with ASD

Guidance Notes for MAP Completion

While you can't predict when an emergency may happen, you can be prepared. Maintaining a personal medical binder is key to ensuring you receive optimal healthcare support. Your Binder should include basic information (name, date of birth, blood type, and immunization records), emergency contacts, healthcare providers, diagnoses, allergies, medications, insurance information, preferred documents and vital documents (e.g., Living wills, advance directives, medical power of attorney, and DNR orders).

While maintenance of this binder, with up to date and accurate information is important, it is also best to find a way to ensure your most pertinent information can be easily reviewed.

Your Medical Alert Passport (MAP) is intended to help hospital staff provide you with the best, personal emergency room, inpatient, and outpatient care, when needed.

It is most important to fully complete your **MAP** now, versus waiting until you may require an emergency room visit or hospital stay, when it might be more difficult to complete while under such stress.

Once your **MAP** is complete print out 2-3 copies and place within your medical binder (in a safe and accessible place).

If and when you do find yourself at the hospital, show your **MAP** to the doctors, nurses and any other healthcare professionals affiliated with your case. If you're admitted to the hospital, ask the nurse to keep your **MAP** with your notes at the end of your bed and to make sure it is reviewed with each new staff member who comes on shift.

Remember: Don't forget to update your Medical Alert Passport (MAP)!

Ensure any / all changes in medication or medical conditions are updated.

Please use the following guidance notes to help you (and/or any other important people in your life) complete your **MAP** with **the most beneficial information** for healthcare professionals to use when they are assessing and treating you.

The questions listed are designed to prompt you to think about what might be important for you. It is best to note specific detail about your needs and how these can be met (versus answering "yes" or "no").

Remember: While in the hospital, your doctors and nurses need to treat you as quickly as possible. Your doctors and nurses are very busy and may not have time to read a lot of information.

Only write down the most important information to allow doctors and nurses to help you.

Personal Information and Contacts

Use the information below to guide you in completing the personal information and contact portion of MAP:

Name:

- Please indicate your full name

What do you like to be called:

- Please indicate the name you like to be called or will most likely answer to (your nickname)

What is your Caregiver's Name and Phone number:

- If there's someone for whom it's important for hospital staff to speak with about your care, or who should be accessible to you during hospital or emergency room stay, fill in their name and contact information here.
- This person could be someone such as your partner, parent, caregiver, or other family member.
- This should be the primary person who can help you communicate with medical personelle if needed.

Do you have any known allergies:

- Please list any allergies you have been diagnosed with
- This should include medications and non-medication allergies (e.g., tree nuts, latex, etc.)

Do you have any dietary restrictions:

- Please list any dietary restrictions you follow in your every day life and would like to adhere to while in the hospital. This area should not contain things you are allergic to.
- This could include things such as Vegan, Kosher, no dairy

Do you have a history of Seizures?

- Indicate **Yes** if you have a history of seizures and **No** if you have not had seizures
- Under description indicate things such as "controlled by medication", "last one was 5 years ago", "only febrile seizures", and identify possible associated factors (time of the month, stress, etc...)



Medication(s)

My Current Medications:

- List all the current medication you take.

Medications I don't respond well to:

- Sometimes it can be unhelpful or even dangerous to make changes to or stop someone's medication without knowing all the right information.
- Please list any medications that you have tried in the past and that you did not respond well to so hospital staff can be sure to avoid these medications in the future

Please don't make changes in my medications without first talking to my prescribing physician:

- If there is someone that hospital staff should speak with before making any changes to your medication (e.g., your GP or psychiatrist), put their name, role (e.g., psychiatrist, GP, neurologist, etc.) and phone number in your passport.



Communication

Successful communication with the hospital staff demands effective two-way communication. It is important to be able to convey the specific methods that work best for you to share information and the ways you are best able to interpret what is being said.



How would you like to communicate with hospital staff?

- Will you talk back to them?
- Will you need to write the answers down?
- Will you need to use a communication APP on your tablet or other device?
- Would you prefer to use pictures or symbols?
- Will you be able to point at things or demonstrate them?
- Would you prefer that your caregiver answers the questions?

How would you like for hospital staff to communicate with you?

- Can they ask you questions?
- Do the questions need to be short and very specific?
- Do they need to write things down for you?
- Would you prefer pictures or symbols?
- Will it help if they point at things or demonstrate things?
- Will you need some time to think about the question before you can answer it?
- Do you need extra time when asked questions?
- Is it helpful to list what they will be doing?
- Is it helpful to note how long something will take, and if so, how best to denote the length of time (clock, stopwatch, timer, etc....)?
- Should they ask your caregiver to help explain things to you?



Pain

One of the ways that doctors and nurses know what is wrong with you and how to treat you is by your experience and description of pain. They will, therefore, ask you lots of questions about pain and ask you if you feel any pain when they examine you.

How do you experience pain?

- Do you experience pain?
- What do you do when you experience pain?
- If you don't experience pain, how do you know when you are unwell or ill?

How do you communicate pain?

- Will you be able to tell the doctors and nurses that you have pain?
- How will you tell them? What words will you use?
- Will you be able to describe the pain?
- Will you be able to point to where the pain is?
- Do you become very quiet and withdrawn when you are in pain?
- Or do you become very upset and maybe even angry or appear aggressive?



Sensory/Environment

Hospital staff will need to examine you and carry out tests. This will involve touching you with their hands and using various equipment.



What are some things that bother you or cause you distress/anxiety?

- Are you fearful of needles or any other things related to hospital check-ups?
- Do you dislike people getting too close to you?
- Do you find physical touch unpleasant or distressing?
- Do you find the smell or feel of rubber gloves unpleasant or distressing?
- Some of the equipment will be hard and cold – will this be a problem for you?
- Do you dislike bright lights, especially if they are shining in your eyes?
- Do you dislike tight things such as blood pressure cuffs?
- Do you dislike wearing things around your wrist (hospital ID band), neck or ankle?
- Do you dislike having your blood taken?
- Will you find it difficult being in an enclosed space, such as a scanner?
- Do you have difficulty swallowing tablets?

What are some things that may help you to stay calm and cope?

- Can you cope with bright lights if you are given warning and support – what sort of support?
- Can you cope with the unpleasant noise(s) if you are given warning and support – what sort of support?
- Can you cope with tight things if you are given warning and support – what sort of support?
- Can you cope with having your blood taken if you are given warning and support – what sort of support? Does anesthetic cream help?
- Can you cope with enclosed spaces if you are given warning and support – what sort of support? Would ‘calming’ medication help?



What are some things that make you happy?

- What is your favorite food or snack item when you aren't feeling well?
- What beverages do you enjoy having?
- What is your favorite song? What is your favorite artist/genre of music?
- How do you spend your leisure time (hobbies)? What interests do you have?
- Do you have any comfort items?
- Are there any specific routines you try to stick to?

What are some other important things hospital staff should know about you?

- When anxious do you exhibit certain behaviors (talk to yourself, become overly quiet or overly talkative, tend to pace, tend to rock, etc...)?
- Sleep and eating patterns (rituals/routines)?
- Is there anything that will upset you (particular words or phrases, specific actions/behaviors of others)?



Safety

The doctors and nurses aim to keep you safe during your stay at the hospital. Therefore, it is important to list any safety concerns you may have.



Do you have a history of PICA?

- List any non-food items that you may ingest, such as: rocks, dirt, feces, paper, etc.
- Include any non-food items you tend to put in / hold in your mouth that might increase choking.

Do you have a history of elopement?

- Are you likely to wander from, run away from, or otherwise leave a caregiving facility or environment?

Do you have a history of aggressive or self-injurious behaviors?

- What self-injurious behaviors have you engaged in in the past? (i.e., biting, scratching, head banging, hair pulling, etc.)
- What aggressive behaviors have you engaged in in the past? (punching, pushing, slapping, spitting, etc.)
- Are there known triggers for these types of behaviors?

Additional Information

Use the back sheet of your **MAP** to elaborate on any information noted on the front and/or to list other things that it will be helpful for hospital staff to know about you.

For example:

- Any special interests you need to follow, such as TV programs
- Any sensory needs that you haven't mentioned already
- Anything else that might cause you distress or anxiety
- Do you need help washing or dressing?
- Any spiritual or cultural needs



About the Emory Autism Center

Autism Spectrum Disorder (ASD) affects individuals differently. We focus on each child and adult as a capable and active learner with unique strengths and talents. Everyone learns best when they are having fun and through discovery. We combine this philosophy with the latest research to support meaningful improvements in quality of life for individuals with ASD across the lifespan

Mission

To be a valued resource for people with ASD, their families, professionals, and others from the earliest signs of ASD throughout the lifespan by providing affordable, accessible, evidence-based, and useful services and information to each person we serve, and by increasing capacity for support within local communities across Georgia.

Vision

Supporting meaningful improvements in quality of life for individuals with ASD across the lifespan.

Values		
Inclusion	Meaningful Results	Quality of Life
Respect	Evidence-based	Safety
Choices	Positive Behavior Supports	Natural Environments
Lifespan	Personal Relevance	Independence & Community


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If you have any feedback, suggestions, or improvements for the Medical Alert Passport (MAP), please email us at: contact.eac@emory.edu