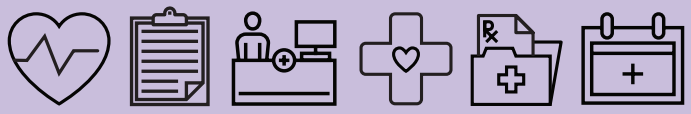
HEALTHCARE JOURNEY BINDER



Introduction

THE ONTARIO caregiver ORGANIZATION

Consent, Privacy & Confidentiality Reminder

As a caregiver, this *Healthcare Journey Binder* provides worksheets that ask for information related to your care recipient's personal health information. The Ontario Caregiver Organization recognizes that you can receive and record this important information based on a couple of scenarios:

(1) The capable care recipient [patient] has authorized their healthcare provider to share their personal health information with you[1]

(2) The care recipient [patient] has been found incapable under the *Health Care Consent Act* to consent to treatment (or admission to long-term care/personal assistance services) or under the *Personal Health Information Protection Act, 2004* (PHIPA); and you are, or another person is, the highest-ranked substitute decision-maker. The substitute decision-maker gives or refuses consent for the collection, use or disclosure of personal health information of the care recipient [patient].[2] If you are not the substitute decision-maker, the person who has that role takes over any information decision-making.

If there is a decision to be made about collection, use or disclosure of personal health information (e.g., release of a test result to a third party such as an insurance company), and the care recipient [patient] is capable, they decide whether to share it; or if incapable, the substitute decision-maker decides.

The Ontario Caregiver Organization encourages you to ask your care recipient's healthcare providers for a copy of their written consent/release of information form or Consent to Disclose Personal Health Information form for your care recipient to sign; or ask the healthcare providers to ask the care recipient [patient] verbally for their consent and document the care recipient's [patient's] consent in their health record. It is also important to make sure that healthcare providers are aware of the documented consent.

Even when the care recipient [patient] has consented that their information can be shared with their caregiver, some caregivers still struggle to get timely information from health care providers. Sometimes healthcare providers need reminders that they are permitted to share certain information with caregivers based on the consent of the care recipient [patient] or substitute decision-maker, or that in some cases, no consent is needed because PHIPA or another Act permits the information to be shared.[3]

Caregivers should keep what is recorded within the *Healthcare Journey Binder* confidential and secure. Written records within the *Healthcare Journey Binder* should not be shared with another party without the consent of the care recipient [patient] (unless you have either their or their substitute-decision maker's consent – if you are the substitute decision-maker, you have authority to share).

[1] Making Privacy and Consent Rules Work for Family Caregivers. 2017. The Change Foundation. Retrieved from: https://www.homecareontario.ca/docs/default-source/publications-mo/privacy-and-consent-report_final-2107.pdf?sfvrsn=4
[2] Ibid 1
[3] Ibid 1

Contents of this binder include:

Personal Information

Medications, Therapies & Allergies

Medical History, Vital Signs & ADL/IADLs

Consent & Legal Matters

Healthcare Team & Notes

Care Templates

What is the Purpose of the Healthcare Journey Binder?

The Healthcare Journey Binder was created by caregivers and healthcare providers to help improve the overall healthcare experience for people with an illness, disease, or medical condition. It can be used by anyone, including caregivers, to manage important healthcare information by:

- Having a place where documents and information can be kept in one place
- Making it easy to organize and find health information
- Allowing you to easily share any information with the healthcare team
- Helping to give you a sense of control

How Does the Binder Work?

Every healthcare journey is different! The Healthcare Journey Binder contains templates created by caregivers and other healthcare organizations.

"Make the Healthcare Journey Binder work for you, the person you provide care for and others involved. These needs may change as this healthcare journey progresses. Freely modify the contents as you go to make them work best for you." - Caregiver

You can modify your binder by:

- Moving the binder sections into an order that you find helpful
- Adding or removing sections and templates
- Storing documents and papers in the binder or envelope provided

The Caregiver Role

A caregiver is defined as a family member, friend and/or neighbour who provides personal, social, psychological and physical support, assistance and care, for family members and friends in need. This support can be provided for any length of time.

Caregiving can include coordinating medical appointments, managing medications, arranging in-home healthcare services, and many other tasks.

"Often, being a caregiver can seem like an overwhelming and all-consuming experience. The Healthcare Journey Binder can become one of your most useful tools and resources, helping you and the person you are providing care for reduce stress and enhance your journey together." - Caregiver

A Word of Thanks

Connecting the Dots for Caregivers was a partnership of six health care organizations in Huron Perth, funded by the Change Foundation. Together, with caregivers, they worked to improve the caregiver experience by co-designing solutions, programs and resources that will ensure caregivers feel valued, respected, engaged and supported in their important role.

The **Healthcare Journey Binder** is just one of many resources created through a co-design process involving equal participation of caregivers and healthcare providers. A special thanks to all of those who participated. Thanks to the caregivers from the Ontario Caregiver Organization's Mental Health Working Group **for their help in updating this second edition** to ensure continued value as a support to all caregivers. For additional caregiver resources, please go to www.ontariocaregiver.ca

Contact for Binder Support:

Name/Organization:

Position:

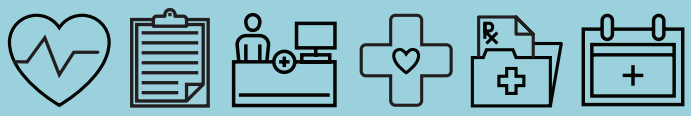
Phone Number:

E-mail address:

Province-Wide Support		
Resource	**Description**	**Contact Information**
Ontario Caregiver Organization - Helpline	The Helpline is available 24/7 and aims to provide a one-stop resource for information and support. Whether you are looking for respite care in your area, a support group, information about financial supports available to caregivers, as well as help navigating the health and social service systems, the helpline is here to connect you to the resources you need.	1-833-416-2273 (CARE)
Local Health Integration Network (LHIN) - Home and Community Care	The Local Health Integration Network (LHIN) is spread across Ontario to ensure you can receive local resources that fit your needs. The LHIN can help if you, or someone you care about, needs health care services at home, at school or in the community, or if you are considering supported living programs or long-term care options, home and community care. They can also link you to providers in your community for specific information and local support.	Find your LHIN - Home and Community Care by entering your postal code: http://healthcareathome.ca/ Depending on your region, each LHIN will have a specific number you can call.
Financial Resources		
Government of Canada - Tax credits for family caregivers	If you have a dependent with a physical or mental impairment, you may be eligible for the Family Caregiver Amount tax credit.	https://www.canada.ca/en/financial-consumer-agency/services/caring-someone-ill/tax-credit-caregiver.html
Government of Canada - Basic Personal and Dependent Tax credits	If you have a dependent with a physical or mental impairment, you may be eligible for the Family Caregiver Amount tax credit.	https://www.canada.ca/en/revenue-agency/services/tax/technical-information/income-tax/income-tax-folios-index/series-1-individuals/series-1-individuals-1/income-tax-folio-s1-f4-c1-basic-personal-dependant-tax-credits.html
Government of Canada - EI Caregiver Benefits and Leave	Through Employment Insurance, you could receive financial assistance of up to 55% of your earnings, to a maximum of $573 a week. These benefits will help you take time away from work to provide care or support to a critically ill or injured person or someone needing end-of-life care.	https://www.canada.ca/en/services/benefits/ei/caregiving.html

Veterans Affairs Canada - Caregiver Recognition Benefit	Having a disability sometimes means you need ongoing care to remain in your home. The Caregiver Recognition Benefit recognizes the important role a caregiver delivers on a day-to-day basis by providing them $1,000 per month, tax free.	https://www.veterans.gc.ca/eng/housing-and-home-life/help-at-home/caregiver-recognition-benefit
Legal Support, Privacy and Consent		
Government of Ontario - Consent to Disclose Personal Health Information	It is reasonable for you to ask the patient you are caring for to consent to their healthcare provider sharing personal health information with you. Print this form for the patient to sign or ask the provider to document the patient's consent in their health record and make sure that the provider's staff is aware of the documented consent.	http://www.health.gov.on.ca/english/providers/project/priv_legislation/consent/consent_disclose_form.pdf
Ministry of Attorney General - Capacity Assessment	**Capacity Assessment** is the formal assessment of a person's mental capacity to make decisions about property and personal care. Many situations require capacity assessments to be conducted by specially qualified assessors who must follow specific guidelines.	https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/incapacity/capacity_assessment.php
Ontario Ministry of the Attorney General - Power of Attorney	A Power of Attorney is a legal document in which you give someone you trust (called your "attorney") the right to make decisions for you if something happens and you are no longer able to look after matters on your own.	https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/incapacity/poa.php

HEALTHCARE JOURNEY BINDER



Personal Information

THE ONTARIO caregiver ORGANIZATION

Name:

Address:

Home Phone Number: Cell Phone Number:

E-mail Address:

Language Spoken/Read: Birthdate:

Family Doctor: Phone Number:

My Parent/Legal Guardian Name:

Custody Concerns/ Arrangements: ☐ Single ☐ Joint

Phone Number(s):

Address:

Email Address:

My Parent/Legal Guardian Name:

Phone Number(s): Address:

Email Address:

Power of Attorney for Personal Care Name:

Contact Information:

Contact Information for Lawyer:

Primary Caregiver Name & Relationship (e.g. spouse, friend, son):

Contact Information:

Hours of Work & Work Contact Information (if applicable):

Secondary Caregiver Name & Relationship (e.g. spouse, friend, son):

Contact Information:

Hours of Work & Work Contact Information (if applicable):

Special Considerations

- [ ] Developmental Delay
- [ ] Developmental Disability
- [ ] Intellectual Disability
- [ ] Custody Concerns
- [ ] Uses Sign Language
- [ ] Non-Verbal
- [ ] Eye Gaze Choices
- [ ] Cultural Considerations
- [ ] Aggression
- [ ] Uses a Mobility Device
- [ ] Risk for Falling
- [ ] Unable to Walk
- [ ] Mental Health
- [ ] Hearing Impairment
- [ ] Dementia/Alzheimer's
- [ ] Roaming Risk
- [ ] Visually Impaired
- [ ] English as Second Language
- [ ] Addictions
- [ ] I have a Care Plan or Coordinated Care Plan (e.g. Health Links)

Facts About Me

My Nicknames:

My Family

Where I Live or Have Lived

What TV Shows or Movies Do I Like?

What I Like to Do (e.g. reading, games, sports, activities, etc.):

What Kind of Music I Like:

Other Information About Me:

Care Considerations

When planning or providing care, it's important to understand how to make you and your environment as comfortable as possible. Use this section to write down any 'triggers' that might cause you to feel or react in negative way.

Trigger	Reaction	Possible Alternatives
e.g. Loud noises	e.g. Anxiety or agitation	e.g. Keeping the door shut when possible; Turning volume down on in-room alarms

HEALTHCARE JOURNEY BINDER

Medications, Therapies & Allergies

THE ONTARIO caregiver ORGANIZATION

Why is this Section Important?

It's important to keep an up-to-date record of current medications, vaccines, allergies, and alternative and complimentary therapies that can be easily shared with the healthcare team.

This is important because this record can:

- Decrease medication errors or bad reactions
- Help prevent allergic reactions
- Decrease how often you have to tell people this information
- Help your healthcare team better understand your complete healthcare journey

By recording this information, you will be able to quickly access and share this with members of the healthcare team.

What information do I need to record?

Allergies and Sensitivities

Throughout your healthcare journey, you will often be asked about any allergies you might have. Having a list that can quickly be accessed is an easy way to share this information.
Healthcare providers will want to know about any type of reaction you might have had including reactions to medication, food, or the environment (e.g. seasonal allergies).

Medications, Complementary and Alternative Therapies

Having a current medication list that can be quickly shared with your health team can help to reduce medication errors or bad reactions. This record is also helpful to healthcare providers as it provides the most up-to-date record of what medications are being taken and when. It's also important to include lists of vitamins or supplements, complementary and alternative therapies (such as massage or acupuncture), as these therapies are essential to consider in relation to medication and treatment plans.

Vaccines or Immunizations

Immunization or vaccine history is another valuable resource to keep up to date. Healthcare providers will want to know which vaccines are up to date including influenza (the 'flu' shot), pneumonia and shingles vaccines. Keeping an up-to-date immunization record (such as the 'Yellow book') in this section is another option.

How to Use this Section

Use and adapt this section to fit your needs. Every healthcare journey is different. Some examples of ways to use this section include:

- Keep medication records printed from your doctor, pharmacy or from the hospital in this section
- Ensure that you remove older versions of printed medication lists to avoid any confusion
- Review the questions to ask your pharmacist to better understand your existing medication or new medication you will be taking
- Remember to dispose of old medical information securely. Ask your pharmacy to dispose of old medication and old medication lists

5 Questions to Ask about your Medications

Did you know??

Medication errors or mistakes are most likely to happen when moving throughout the healthcare system – such as being admitted or discharged from hospital.[1]

For this reason, organizations such as the Institute for Safe Medication Practices in Canada, Patients for Patient Safety Canada, the Canadian Pharmacists Association, and the Canadian Association for Hospital Pharmacists have worked together to develop 5 questions to help patients and caregivers start a conversation with their healthcare team about their medications.[2]

Use the questions below when talking with any member of your healthcare team about your medications. This includes doctors, nurses, and pharmacists

1. Changes?
Have any medications been added, stopped or changed, and why?

2. Continue?
What medications do I need to keep taking, and why?

3. Proper Use?
How do I take my medications, and for how long?

4. Monitor?
How will I know if my medication is working, and what side effects do I watch for?

5. Follow-Up?
Do I need any tests and when do I book my next visits?

[1] Institute for Safe Medication Practices Canada. (2011, February 10). *Optimizing medication safety at care transitions – Creating a National Challenge*. Available from: https://www.ismp- canada.org/download/MedRec/MedRec_National_summitreport_Feb_2011_EN.pdf
[2] Institute for Safe Medication Practices Canada. (2016). 5 *questions to ask about your medications when you see your doctor, nurse, or pharmacist*. Available from: https://www.ismp-canada.org/medrec/5questions.htm

Allergies and Sensitivities

An **allergy** means your body sees the medicine as harmful. It rejects the drug with an allergic reaction. This can be mild or strong. It can happen within a few hours after you take the drug or not until 2 weeks later. A sensitivity or side effect is not the same thing as an allergy – it's just your body feeling sensitive to a new medication. Some examples of sensitivities include feeling sick to your stomach, having muscle aches, not having much energy or affect your thinking and behaviours.[3]

Allergy or Sensitivity	What Happens?

[3] Web MD. (2017). *Is it a drug allergy or a side effect?* Available from https://www.webmd.com/allergies/allergy-or-side-effect?print=t

Current Medication Record

It is important to list **all medications** you take including both prescription and over the counter medications in this chart.

Pharmacy Address: _____

_____

Pharmacy Phone # _____

Pharmacy Fax # _____

Name and Dose	Reason	Instructions (include frequency and route of administration)	Side-Effects	As Needed	Break-fast	Lunch	Dinner	Bedtime	No Longer Taking	Last Updated (dd/mm/yy)
e.g. Tylenol 250mg	e.g. Muscle Pain	Take one pill every 4hrs when sore through oral administration	What are they? When did they start? Best way to reduce them?	☐	☐	☐	☐	☐	☐	8/12/18
				☐	☐	☐	☐	☐	☐	
				☐	☐	☐	☐	☐	☐	
				☐	☐	☐	☐	☐	☐	
				☐	☐	☐	☐	☐	☐	

Name and Dose	Reason	Instructions (include frequency and route of administration)	Side-Effects	As Needed	Break-fast	Lunch	Dinner	Bedtime	No Longer Taking	Last Updated (dd/mm/yy)
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				☐	☐	☐	☐	☐	☐	
				☐	☐	☐	☐	☐	☐	
				☐	☐	☐	☐	☐	☐	
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				☐	☐	☐	☐	☐	☐	
				☐	☐	☐	☐	☐	☐	
				☐	☐	☐	☐	☐	☐	

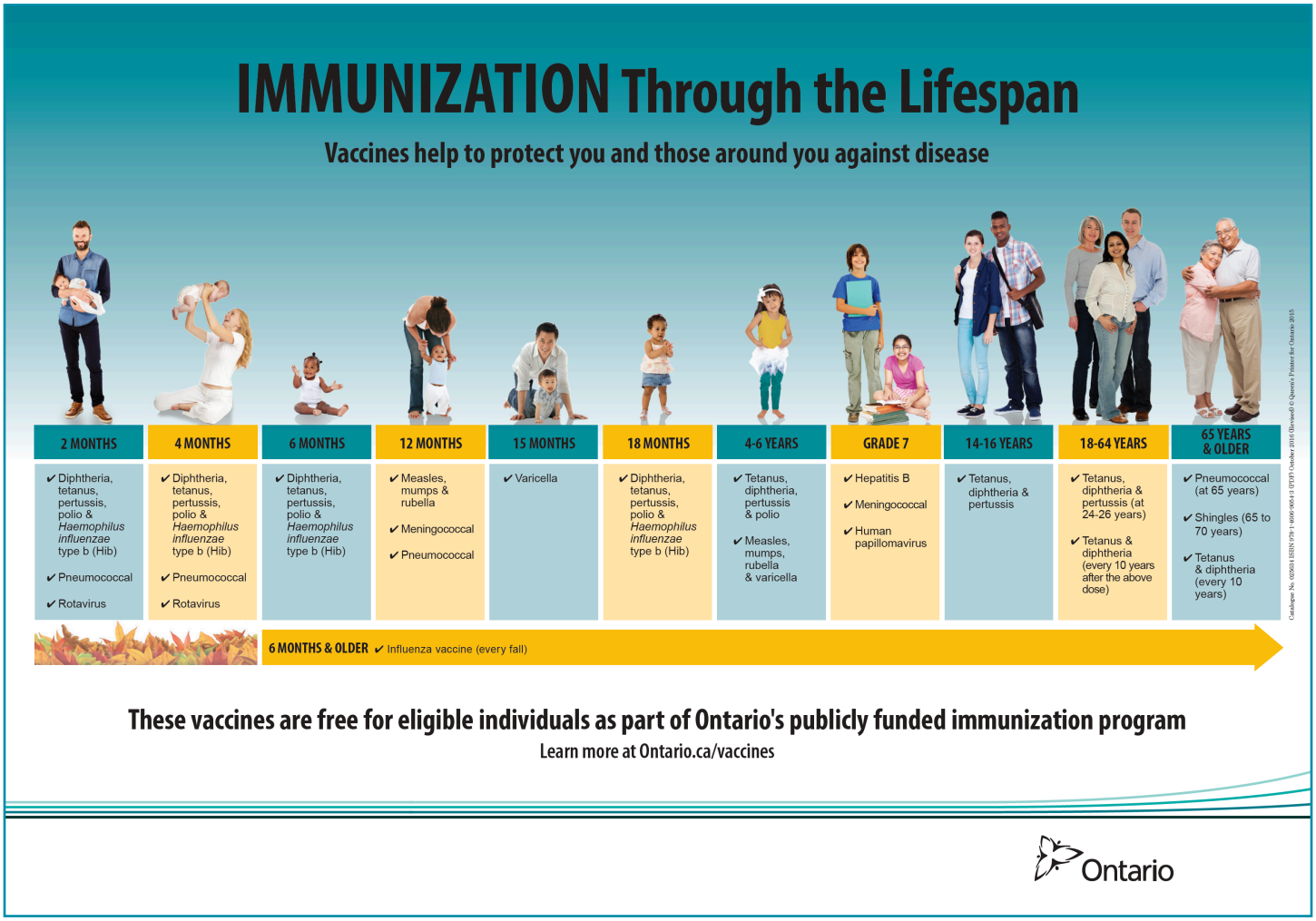
Vitamins and Supplements

List **all** vitamins and supplements you take in this chart

Name and Dose	Reason	Instructions (include frequency and route of administration)	As Needed	Break-fast	Lunch	Dinner	Bedtime	No Longer Taking	Last Updated (dd/mm/yy)
e.g. Vitamin D	e.g. Bone health	e.g., Take one pill daily orally	☐	☐	☐	☐	☐	☐	8/12/18
			☐	☐	☐	☐	☐	☐	
			☐	☐	☐	☐	☐	☐	
			☐	☐	☐	☐	☐	☐	
			☐	☐	☐	☐	☐	☐	
			☐	☐	☐	☐	☐	☐	
			☐	☐	☐	☐	☐	☐	

Vaccination Information

Keep a copy of your vaccination records in the pocket of this binder. Below is some information on which vaccines or immunizations are needed throughout your lifetime.[4]



[4] Government of Ontario. (2016). Retrieved from: http://www.health.gov.on.ca/en/pro/programs/immunization/docs/immunization_poster_lifespan.pdf

Alternative or Complimentary Therapies

A complementary therapy is something you do or use alongside your conventional medical treatment.[5]

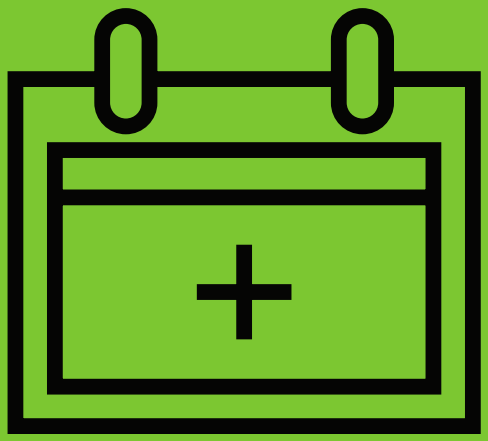
An alternative therapy is something you do or use instead of conventional medical treatment[1].

Some examples include: aromatherapy, acupuncture, herbal medicine, massage therapy, visualization, exercise (e.g., yoga, walking, swimming).

Type of Therapy	Reason	Instructions	Details of Practice
e.g., walking	e.g., boosts mood and helps alleviate joint pain	e.g., 3x/week for 30mins	e.g., walks outside, around the neighborhood

[5] Cancer Research UK. (2018). The difference between complementary and alternative therapies (CAMS). Retrieved from: https://www.cancerresearchuk.org/about- cancer/cancer-in-general/treatment/complementary-alternative-therapies/about/difference-between-therapies

HEALTHCARE JOURNEY BINDER



Medical History, Vital Signs & ADL/IADLS

THE ONTARIO caregiver ORGANIZATION

About this section

Why is this Section Important?

Medical histories and key dates can be difficult to remember. However, information about your **medical history** including diagnosis, hospitalizations, surgeries and other information are important for your healthcare team to know.

This section is a place where you can document and quickly access your medical history when asked by your healthcare team.

How to Use this Section

Use and adapt this section to fit your needs. Every healthcare journey is different.

Personal Medical History
Some caregivers have said that adding historical information can be a lot of work. With that in mind, in this section you can choose to:

- Add notes about diagnoses, hospitalizations and surgeries starting today and keep the binder up-to-date going forward.
- You can choose to add past procedures to the best of your knowledge. Include dates and other details about past diagnoses and reactions where you can and as you feel it's appropriate

Vital Sign Notes and Tracking Calendar
In this section, we have included an area for you to record your 'vital signs'. **Vital signs** are a basic measure of overall health and can be a source of important information for your healthcare team. Examples of vital signs include blood pressure, heart rate, and weight. **This information lets your healthcare team know what is normal for you!** A record of vital signs is not needed for every person. Speak to your healthcare team to see if such a record would be helpful for you.

Activities of Daily Living and Instrumental Activities of Daily Living
It may also be important for you to record your 'Activities of Daily Living' and 'Instrumental Activities of Daily Living'. **Activities of Daily Living** are the tasks of everyday life. These include bathing, eating, and dressing. **Instrumental Activities of Daily Living** refers to those tasks that are needed to live independently. Keeping a record of these tasks can be helpful for your healthcare team since it lets them know how much help you might need. Depending on the diagnosis or stage of illness you may not need to use this part of the binder.

Personal Health History

Diagnoses		
Year	Name of Diagnosis or Concern	By Who (e.g. physician's name, etc.)?
Any other pertinent information related to diagnosis?		
Diagnoses		
Year	Name of Diagnosis or Concern	By Who (e.g. physician's name, etc.)?
Any other pertinent information related to diagnosis?		
Diagnoses		
Year	Name of Diagnosis or Concern	By Who (e.g. physician's name, etc.)?
Any other pertinent information related to diagnosis?		
Diagnoses		
Year	Name of Diagnosis or Concern	By Who (e.g. physician's name, etc.)?
Any other pertinent information related to diagnosis?		

Personal Health History

Hospital Visits		
Year	Reason	Name of Hospital
		☐ Emergency Department Visit Only ☐ Admitted to Hospital
		☐ Emergency Department Visit Only ☐ Admitted to Hospital
		☐ Emergency Department Visit Only ☐ Admitted to Hospital
		☐ Emergency Department Visit Only ☐ Admitted to Hospital
		☐ Emergency Department Visit Only ☐ Admitted to Hospital

Personal Health History

Surgeries & Procedures		
Year	Procedure/Reason/Notes	Name of Hospital

Vital Signs

Use this template to record any important details about vital signs.

Date	Blood Pressure	Heart Rate (Beats per minute)	Respiratory Rate (Breaths/ minute)	Weight	Pain or Discomfort	Oxygen Level (Saturation)	Bowel Movements

Activities of Daily Living (ADL)

The term, 'Activities of Daily Living' (ADL) refers to everyday personal activities. Examples include bathing, eating and drinking, and walking.[1] Use the chart below to track your ability to complete ADLs. This is important information to share with your healthcare providers to provide and plan care. It should also be updated over time as ADLs may change.

	No Help Needed	Some Help Needed	Complete Help Needed	Not Applicable
Example (Bathing)	e.g. face and arms	e.g. rest of body	e.g. hair washing and back	
Bathing or Showering				
Dressing				
Grooming				
Mouth Care				
Toileting				
Transferring Bed/ Chair				
Walking				
Climbing Stairs				
Eating and Drinking				

[1] Adapted from: Senior Planning Services. (2013). ADL/IADL Checklist. Retrieved from: https://www.seniorplanningservices.com/files/2013/12/Santa-Barbara-ADL-IADL-Checklist.pdf

Activities of Daily Living (IADL)

The term 'Instrumental Activities of Daily Living' (IADL) refers to activities which allow a person to live independently.[2] Use the chart below to track ability to complete IADLs. This is important information to share with your healthcare providers to provide and plan care. It should also be updated over time as IADLs may change.

	No Help Needed	Some Help Needed	Complete Help Needed	Not Applicable
Example (Shopping)	e.g. Make own list and visit store	e.g. Needs help finding items, loading in cart and paying	Shopping	
Shopping				
Cooking				
Managing Medications				
Using a Phone				
Housework				
Laundry				
Transportation				
Managing Finances				

[2] Adapted from: Senior Planning Services. (n.d.). ADL/IADL Checklist. Retrieved from: https://www.seniorplanningservices.com/files/2013/12/Santa-Barbara-ADL-IADL-Checklist.pdf

HEALTHCARE JOURNEY BINDER

Consent & Legal Matters

THE ONTARIO caregiver ORGANIZATION

About this section

Why is this Section Important?

This section includes information about some of the legal terms that you may hear in your caregiving journey. The section may not include everything you could need, but these were identified by caregivers as information that's often confusing and important to know.

How to Use this Section

Please use this section as a starting point for conversations with your healthcare providers (and others) about these topics where applicable. T**he information in this section is not to be used as advice or legal counselling**. The information in this section is accurate as of October 2018.

What is a Substitute Decision-Maker?

The Substitute Decisions Act

- The Substitute Decisions Act (SDA) is the law that governs who can make decisions about their i) personal care and ii) personal property when that person is not mentally able to make certain kinds of decisions. The Act covers financial and property management decisions, and decisions about personal care, which include health care, food, housing, safety, as well as end-of-life decisions.[1]
- A person who makes decisions for another person is called a **Substitute Decision Maker**. This person is someone who is given the legal authorization to make personal care decisions on behalf of that person. The need to take such a step could be caused by illness, accident or disability, a temporary condition or a permanent one.[1]
- In Ontario everyone automatically has a **Substitute Decision Maker**. Under the act, healthcare providers obtain consent from the person highest on the following list:
    1. Guardian of person with authority for treatment
    2. Attorney named as a Power of Attorney for Personal Care
    3. Representative appointed by the Consent and Capacity Board
    4. Spouse or Partner
    5. Child, Parent or Children's Aid Society
    6. Parent with right of access only
    7. Brother or Sister
    8. Any other relative by blood marriage or adoption
    9. Office of the Public Guardian and Trustee[1]

What is a Power of Attorney (POA)?

- A Power of Attorney is a legal document that sets out who will be given the right to act on your behalf when you are unable to do so.[2]

Are there different kinds of Power of Attorney?

- Yes. In Ontario there are two kinds of Power of Attorney:
    i. A Power of Attorney for Property (CPOA) covers a person's financial affairs and allows the attorney to act for you even if you become mentally incapable.[2] The CPOA can be one of two types: "continuing" (goes into effect as soon as signed); or it will specify that it takes effect only upon a finding of incapacity.
    ii. A Power of Attorney for Personal Care (POAPC) covers a person's personal decisions, such as housing and health care.[2]

[1] Ministry of the Attorney General, The Office of the Public Guardian and Trustee (2000). A Guide to the Substitute Decisions Act. Ontario: Queen's Printing for Ontario. Available from: https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/pgtsda.pdf
[2] Ministry of the Attorney General. (2017). How Powers of Attorney work. Available from: https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/incapacity/poa.php

How are a patient's wishes captured?

Patients should consider discussing with loved ones and documenting, such as in a Power of Attorney for Personal Care (POAPC), what they would like to happen if they become ill and cannot communicate their wishes about treatment. In Ontario, a POAPC must be written according to specific rules, e.g., it must be witnessed by two people, and it names the 'attorney' who will interpret the patient's wishes.

What is a Do Not Resuscitate - DNR?

Do Not Resuscitate means that the healthcare provider (in accordance with his/her level of certification) will not initiate any of the interventions listed in the definition of CPR, below.[3]

Cardiopulmonary Resuscitation (CPR) An immediate application of life-saving measures to a person who has suffered sudden respiratory or cardiorespiratory arrest. This includes some or all of the following procedures:

- Chest compression
- Defibrillation and/or pacing (application of electrical current to stimulate/regulate heart function)
- Artificial ventilation (e.g. mouth-mouth or assisted ventilation with compression bag)
- Insertion of an artificial airway (to provide significant pathway of oxygen to lungs
- Resuscitation medications that target cardiac function[3]

**** Speak to your Doctor or Nurse Practitioner about DNR to find out more information that can support your decision about this order.**

DNR Confirmation form (DNRC) – *used by firefighters and paramedics only[4]

- This form confirms that the existing care plan does not include CPR
- This is a standardized form in Ontario for first responders to follow (paramedics, firefighters)
- This form is valid when signed by a doctor or nurse. Paramedics and firefighters are not required to review or confirm the actual **DNR** order in the patient/client's health record.
- Form can be used as many times as necessary
- This form is different from the hospital's **DNR** as it is stating whether or not to initiate CPR – hospitals have different levels of care. Once at hospital the physician will further clarify the level of care. This form was created for first responders to have a clear direction on whether or not to initiate CPR.
- The patient or substitute decision maker can rescind **DNR Confirmation Form** at any time.
- Speak to your healthcare provider for more information about filling out a **DNR Confirmation Form**[4]

[4] Do Not Resuscitate Confirmation Form. (2008). [Downloadable form]. *Access from the Central Forms Repository Ontario*. Retrieved from http://www.forms.ssb.gov.on.ca/mbs/ssb/forms/ssbforms.nsf/FormDetail?OpenForm&ACT=RDR&TAB=PROFILE&SRCH=&ENV=WWE&TIT=DNR C&NO=014-4519-45

Personal Health Information Protection Act (PHIPA)

The **Personal Health Information Protection Act** is federal legislation that addresses issues around the collection, use and disclosure of personal health information[5]

Organ and Tissue Donation

When considering your final wishes, it is important to consider organ and tissue donation. To learn more about organ and tissue donation visit the following websites:

- https://www.beadonor.ca/about-donation/faqs
- https://www.giftoflife.on.ca/en/

To register for organ and tissue donation in Ontario:

- https://www.ontario.ca/page/organ-and-tissue-donor-registration

Lawyer Name/Firm: _____

Telephone Number: _____

E-Mail Address: _____

[5] Cavoukian, A (2004) A Guide to the Personal Health Information Protection Act—Rev. Toronto, Ontario: Information and Privacy Commissioner/Ontario

HEALTHCARE JOURNEY BINDER

Healthcare Team & Notes

THE ONTARIO caregiver ORGANIZATION

About this section

Why is this Section Important?

This section provides a clear way to keep track of details about appointments, tests and procedures and community provider visits so that a caregiver/family member can make arrangements to accompany you, provide transportation and support. Details about scheduled appointments, as well as previous information and notes can be valuable when planning appointments and/or tests.

In the days leading up to healthcare appointments, you often think of questions that you may want to ask. More often than not, these are forgotten when the appointment starts, unless they are written down in advance. There is an area to keep track of questions for each appointment. You are an advocate for yourself and/or the person you're caring for. These tools can help you in that role.

How to Use this Section

Use and adapt this section to fit your needs. Every healthcare journey is different.

My Community Care Team

This template provides a reference resource to keep track of your community care providers. In each of the bubbles you can include contact information for each person or organization. This can also give you an idea of what community resources are available and allow you to discuss with your providers about the potential role that they may have in you or your care recipient's health care.

Healthcare Appointments

Fill out the sections under healthcare appointments to keep information about upcoming and past appointments.

Questions to Ask Healthcare Providers

Caregivers can be advocates for the person they care for. Here are four questions to consider asking when you interact with healthcare providers:

1. What is the main concern today?
2. What needs to be done next?
3. Why is it important to do this?
4. Who can I contact if I have questions?

Tests and Procedures

Fill out the sections under tests and procedures to keep information about tests and procedures. Recording notes – how it was tolerated, issues with preparation or recovery, etc. – can help when you schedule or plan future tests and procedures.

Use this section to place things like parking receipts and upcoming appointment cards until you can log them along with any information received from health care providers.

Notes

Notes pages are included in this section for you to record information as you need to. You could use them during a hospital stay or any other interaction with healthcare providers.

Communication Log

Make use of the communication log during your hospital stay and hospital bedside white board to keep track of questions you have for healthcare professionals. White boards are handy because questions can be left here for answers to be obtained even when you are not present.

Community Provider Visits

This template can be used to keep track of community visits. This can be helpful for future reference of visit dates, but there is also a space for notes that can be helpful during future visits.

Messages I Have for Community Providers

In the days leading up to your next community visit you often think of questions that you may want to ask. More often than not, these are forgotten when the appointment gets going, unless they are written down in advance. This section also provides an area to keep track of questions for community providers.

My Community Care Team

Title (Eg. Psychiatrist)	**Title (Eg. Counsellor/Therapist)**
Organization:	Organization:
Who to Contact:	Who to Contact:
Telephone:	Telephone:
Title	**Title**
Organization:	Organization:
Who to Contact:	Who to Contact:
Telephone:	Telephone:
Title	**Title**
Organization:	Organization:
Who to Contact:	Who to Contact:
Telephone:	Telephone:
Title	**Title**
Organization:	Organization:
Who to Contact:	Who to Contact:
Telephone:	Telephone:
Title	**Title**
Organization:	Organization:
Who to Contact:	Who to Contact:
Telephone:	Telephone:
Title	**Title**
Organization:	Organization:
Who to Contact:	Who to Contact:
Telephone:	Telephone:

Healthcare Team Descriptions

Care Coordinators or Case Managers	Social Workers
They are responsible for assessing, planning, coordinating, implementing and reviewing patients' needs and services. They provide information to patients as well as referring them to alternate community resources. They may work for the Local Health Integration Network (soon-to-be Ontario Health Team's) or another community agency.	They help caregivers and their families access services to improve their quality of life and be supported at home or in the community.
Developmental Support Workers	**Personal Support Worker**
They support families who have a child or adult with a developmental disability to help them reach the child's or adult's full potential.	They assist caregivers in-home with daily living that can include bathing, toileting, dressing and feeding.
Respite	**Mobility Services**
Respite provides temporary relief for caregivers to leave for activities or rest. It can include overnight care using respite services outside the home.	They offer safe, accessible and affordable transportation. Services may include volunteer drivers or accessible vehicles.
Family Physician	**Nurse Practitioner**
They see you on a regular basis for check-ups, they diagnose and treat illness, prescribe medications and give referrals.	They can diagnose and treat illness, order and interpret tests, prescribe medication, preventative care and perform procedures.
Nutritional Services	**In-home Nursing**
They deliver food and prepared meals to caregiver homes to ensure a healthy diet and easier preparation.	They offer accredited nurses to help with care planning, medications, wound care and other procedures to help a person with illness or injury.
Occupation Therapists	**Physiotherapists**
They help overcome the physical limitations that interfere with someone's ability to do daily tasks that are important to them.	They treat disease, injury or impairment using exercise, massage and other physical interventions to improve mobility, strength and reduce discomfort.

Speech/Language Pathologist	**Adult Day Programs**
They help assess, diagnose, treat and prevent speech and swallowing disorders.	They offer supervised programming in a group setting and include assistance with personal care.
Psychiatrist	**Psychologist**
They evaluate, diagnose and treat patients with mental, emotional and/or behavioural disorders	They engage in research, practice and reaching across a wide range topics having to do how people think, feel and behave
Psychotherapist	**Counsellor**
They address the root cause and core issues of current problems so that lasting change and personal growth may occur.	They focus primarily on behavior. It often targets a particular symptom or problematic situation and offers suggestions and advice for dealing with it.

Questions to ask my healthcare team

Caregivers can be **advocates** for the person they care for. Here are **four** questions to consider asking when you interact with healthcare providers.

What is the main concern today?

What needs to be done next?

Why is it important to do this?

Who can I contact if I have questions?

Questions to ask my healthcare team

Please write down questions you would like to discuss with your health care team.

My question	The answer I received
The person who answered the question:	
My question	**The answer I received**
The person who answered the question:	

Appointment Tracking Sheet

Appointment Date	Provider Name	Location
Date: Time:		☐ I asked about parking, cost & map
Reason for Appointment	**Supporting Documents to Bring**	**Notes for Appointment**
Questions to Ask (i.e. what is my main problem today, what do I need to do next, why is it important)		
Next Appointment Date		**Follow up Instructions**
Date: ☐ We book Time: ☐ They book		

Appointment Tracking Sheet

Appointment Date	Provider Name	Location
Date: Time:		☐ I asked about parking, cost & map
Reason for Appointment	**Supporting Documents to Bring**	**Notes for Appointment**
Questions to Ask (i.e. what is my main problem today, what do I need to do next, why is it important)		
Next Appointment Date		**Follow up Instructions**
Date: ☐ We book Time: ☐ They book		

Tests and Procedures

Procedure/Test	Date and Time	Location
	Date: **Time:**	☐ I asked about parking, cost & map
Who ordered the procedure/test?		
Notes about procedure prep, response, recovery	**Questions to Ask**	
Follow up:		

Tests and Procedures

Procedure/Test	Date and Time	Location
	Date: **Time:**	☐ I asked about parking, cost & map
Who ordered the procedure/test?		
Notes about procedure prep, response, recovery	**Questions to Ask**	
Follow up:		

Notes

Notes

Communication Log

Question(s) For:	
Date:	
Time:	
Question(s) or Concern(s):	
Response/Follow up:	

Communication Log

Question(s) For:	
Date:	
Time:	
Question(s) or Concern(s):	
Response/Follow up:	

Community Provider Visits

Provider Name and/or Organization	
Visit Date:	
Visit Time:	
This visit has an additional provider binder in the home ☐ Yes ☐ No	
Reason for Visit:	
Next Visit Date & Time:	
Notes:	

Community Provider Visits

Provider Name and/or Organization	
Visit Date:	
Visit Time:	
This visit has an additional provider binder in the home ☐ Yes ☐ No	
Reason for Visit:	
Next Visit Date & Time:	
Notes:	

Community Provider Log

Date	Provider	Notes about Care Provided	See Message Page
			☐
			☐
			☐
			☐
			☐
			☐
			☐

Community Provider Log

Date	Provider	Notes about Care Provided	See Message Page
			☐
			☐
			☐
			☐
			☐
			☐
			☐

Messages I have for Community Providers

To:	
Date:	
Time:	
Message:	
Response/Follow up:	

My mobility

This checklist relates to me ☐

Step 1: Work with your physiotherapist on your mobility goals.
Step 2: Review the Home Exercises Program provided by your physiotherapist.
Step 3: Review the checklist below with your caregiver. If there are areas you or your caregiver have questions about please talk to your **Physiotherapist (PT)**.

What should I and my caregiver know and do about my mobility?	**Patient: I would like more teaching/ practice**	**Patient: I know this/ I can do this safely and confidently**	**Caregiver: I would like more teaching/ practice**	**Caregiver: I know this/ I can do this safely and confidently**	**Health Care Provider**
Can you move yourself in bed? (e.g., rolling, shifting, lie to sit transitions). Do you know how much help is needed to do this?					
Can you move yourself to/from a bed? Do you know how much help is needed to do this?					
Can you move yourself to/from a toilet or commode? Do you know how much help is needed to do this?					
Can you move yourself to/from a bathtub or shower stall? Do you know how much help is needed to do this?					
Can you move yourself to/from a vehicle? Do you know how much help is needed to do this safely?					
Can you move yourself to/from the floor? Do you know how much help is needed to do this safely?					
Do you know how to move throughout your: • Home • Community					
Can you access your home (stairs, ramps, lifts)?					
Can you reposition yourself in your wheelchair?					

My self-care

This checklist relates to me ☐

Step 1: Work with your Occupational Therapist on your self-care goals.
Step 2: Read any materials provided by the Occupational Therapist.
Step 3: Review the checklist below with your caregiver. If there are areas you or your caregiver have questions about please talk to your **Occupational Therapist (OT)**.

What should I and my caregiver know and do about skin health?	**Patient: I would like more teaching/ practice**	**Patient: I know this/ I can do this safely and confidently**	**Caregiver: I would like more teaching/ practice**	**Caregiver: I know this/ I can do this safely and confidently**	**Health Care Provider**
Can you feed yourself? Do you know how to help with this?					
Can you complete your grooming (shaving, brush teeth, wash face)? Do you know how to help with this?					
Can you dress yourself? Do you know how to help with this?					
Can you bathe yourself? Do you know how to help with this?					
Can you complete your toileting (pants up/down & wiping)? Do you know how to help with this? *See the Bowel & Bladder checklist for more information*					

My living skills

This checklist relates to me ☐

Step 1: Work with your Occupational Therapist on your living skills goals.
Step 2: Read any materials provided by the Occupational Therapist.
Step 3: Review the checklist below with your caregiver. If there are areas you or your caregiver have questions about please talk to your **Occupational Therapist (OT)**.

What should I and my caregiver know and do about my living skills?	**Patient: I would like more teaching/ practice**	**Patient: I know this/ I can do this safely and confidently**	**Caregiver: I would like more teaching/ practice**	**Caregiver: I know this/ I can do this safely and confidently**	**Health Care Provider**
Can you prepare your meals? Do you know how to help with the preparation?					
Can you manage your medications? Do you know how to help manage medications?					
Can you do your grocery shopping? Do you know how to help with grocery shopping?					
Can you do your household chores? Do you know how to help do household chores?					
Can you write? If you cannot complete these living skills do you have the necessary supports?					

What I might learn about while I am here

Work with your health care team to develop a plan. Review the checklist below with your caregiver. If there are areas you or your caregiver have questions about please talk to your health care team.

What I need to know about and learn to do	Who is helping me to learn this	My progress	As a family caregiver I need to know more about this care item	Our Notes
		☐ With a lot of help ☐ With some help ☐ With a little help ☐ By myself		
		☐ With a lot of help ☐ With some help ☐ With a little help ☐ By myself		
		☐ With a lot of help ☐ With some help ☐ With a little help ☐ By myself		
		☐ With a lot of help ☐ With some help ☐ With a little help ☐ By myself		
		☐ With a lot of help ☐ With some help ☐ With a little help ☐ By myself		

HEALTHCARE JOURNEY BINDER

Care Templates

THE ONTARIO caregiver ORGANIZATION

About this Section

Why is this Section Important?

Organization will lighten your load! This section is filled with some tools, templates, and resources that can be used to support you in organizing and managing your day-to-day routine and activities.

How to Use this Section

Use and adapt this section to fit your needs. Every healthcare journey is different.

How Friends and Family Can Help

This template provides a resource to use when looking for support. People may offer to help out, but do not know how they can contribute. Keeping a list of duties that you may need support for can serve as a great quick reference resource. Consider letting others have a role to help you complete some of the tasks that you have on your list. Many hands make light work!

Meal Planning Chart

Meal planning is an easy way to save on time. Meal planning has additional benefits including saving money, eating better, and less trips to the grocery store and time cooking. If you or someone you are caring for needs help at meals, this can be a good place to write who and when help is needed.

Daily Routines

This template has been created to record your daily routines. This may be helpful if you have a complicated schedule, or if you require care from multiple people. If you have a caregiver or health providers coming into your home, recording your plan serves as a back-up if you become unavailable to provide care – others can look at the schedule help out as needed.

Body Diagram

The body diagram template can be used to track pain, sensation, strength or anything else that is relevant to you or the person you are caring for.

Typical Week

This is a template for recording your daily routine. This can be helpful as healthcare providers are coming and going to help share with them the tasks that need to be done each day.

Household Routines and Preferences

This template is used to record routines and preferences. For example, do you prefer the temperature of the house is kept a certain way? The blinds are drawn at a particular time? Do you have food preparation preferences (e.g. food should not touch)? These tips about preferences can make the difference in quality of care for you or the person you are caring for and can be shared with anyone who comes into the home.

Calendar Templates

Keeping a calendar is essential to staying organized. This can help you know where you need to go each day and when. Keeping on top of this information can relieve stress, help you prepare for appointments, and avoid double booking. Having a calendar also helps to recognize in advance which days they might need extra support. Use the blank templates, or your own calendar, to keep track of appointments, procedures, hospitalizations, meetings etc. The calendar can be used in any way that suits you.

The templates included in this section are just the start of potential templates that you may find or create to help you on your journey. Feel free to add, modify or replace any contents of this binder with resources that suit your journey.

How Friends and Family Can Help

Task	Who Can Help
e.g. Mowing the Lawn	e.g. George - Neighbour

Meal Planning or Tracking Chart

Date Range: _____

Date range	Monday
Allergies/Dietary Restrictions:	☐ Meal Support Time:
	☐ Meal Support Time:
	☐ Meal Support Time:
Preferences or Considerations:	☐ Meal Support Time:
	☐ Meal Support Time:
	☐ Meal Support Time:

Meal	Tuesday	Wednesday
Breakfast	☐ Meal Support Time:	☐ Meal Support Time:
Snack	☐ Meal Support Time:	☐ Meal Support Time:
Lunch	☐ Meal Support Time:	☐ Meal Support Time:
Snack	☐ Meal Support Time:	☐ Meal Support Time:
Dinner	☐ Meal Support Time:	☐ Meal Support Time:
Snack	☐ Meal Support Time:	☐ Meal Support Time:

Meal Planning or Tracking Chart

Date Range: _____

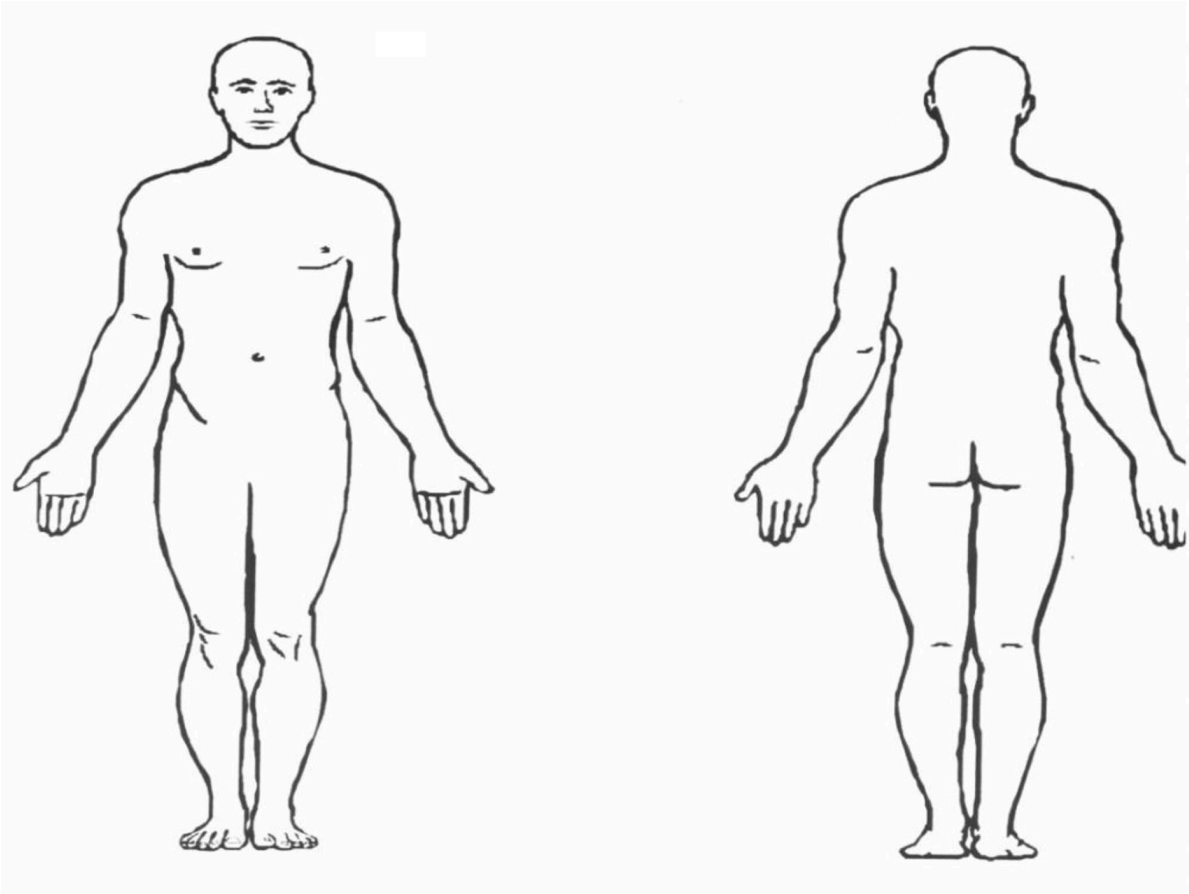
Meal	Thursday	Friday
Breakfast	☐ Meal Support Time:	☐ Meal Support Time:
Snack	☐ Meal Support Time:	☐ Meal Support Time:
Lunch	☐ Meal Support Time:	☐ Meal Support Time:
Snack	☐ Meal Support Time:	☐ Meal Support Time:
Dinner	☐ Meal Support Time:	☐ Meal Support Time:
Snack	☐ Meal Support Time:	☐ Meal Support Time:

Meal	Saturday	Sunday
Breakfast	☐ Meal Support Time:	☐ Meal Support Time:
Snack	☐ Meal Support Time:	☐ Meal Support Time:
Lunch	☐ Meal Support Time:	☐ Meal Support Time:
Snack	☐ Meal Support Time:	☐ Meal Support Time:
Dinner	☐ Meal Support Time:	☐ Meal Support Time:
Snack	☐ Meal Support Time:	☐ Meal Support Time:

Daily Routines

For Me	For My Caregiver
Monday	Monday
Tuesday	Tuesday
Wednesday	Wednesday
Thursday	Thursday
Friday	Friday
Saturday	Saturday
Sunday	Sunday

Body Diagram



Typical Week

	Monday	Tuesday	Wednesday
Morning			
Afternoon			
Night			

Typical Week

	Thursday	Friday	Saturday	Sunday
Morning				
Afternoon				
Night				

Household Routines and Preferences

Household Routines and Preferences
e.g. Please wash your hands in the bathroom sink instead of the kitchen sink e.g. Please leave the thermostat at 22°C

Blank Calendar

Month: Year:

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY