food & mealtime

An inspirational guide for persons with early-stage memory loss and their partners in care

A “By Us For Us” Guide
introduction

Food is an essential part of living – it allows the body to function well. Whether you are shopping and preparing your own meals, or going to a restaurant to eat, it is important to acknowledge and accept changes around food and mealtimes for both persons with dementia and partners in care. For as long as possible, persons with dementia should continue to do and be involved in all aspects of food and mealtimes, from grocery shopping and planning and preparing meals to making decisions on what and where to eat.

Life is so fast paced and sometimes meals become a chore. However, food and mealtimes are more than just feeding our bodies, it is also about nurturing the mind and spirit. Use food and mealtimes to connect with those around you. Use the time to socialize and keep your brain active. Inject humour whenever you can because laughing is good for digestion.

With the inevitable changes, it will be very important to keep the lines of communication open. For persons with dementia, make sure to tell your partner(s) in care how you are feeling and what you want and need from them. For partners in care, it is essential that you ask the person with dementia what they want and need. Also important is to learn to ask for help. The dementia journey is something you do not want to take alone. Reach out for help and support and be specific in identifying to others what kind of support you want and need.

Lastly, don’t forget to congratulate yourselves on the small successes! You deserve it!

Faith Brender, Ron and Anne Hopewell, and Brenda Hounam

By Us For Us Planning Committee
We have dedicated the first section of this guide to shopping and buying food. Shopping, whether it is for food or other necessities, is an inevitable part of life. For some people, shopping is a pleasure, and for others shopping may be more of a chore. For persons with dementia, shopping may present some new challenges, where none existed previously. Being in public can leave persons with dementia feeling very vulnerable. It may highlight to others the loss of ability they may be experiencing. It will be important for both the person with dementia and care partners to acknowledge and accept that things will be different, and that asking for help, although difficult at times, may aid in making the process less stressful and will help everyone to adjust to changing circumstances.

That said, it is important to know that family, friends and store staff are there to support you and your family member with dementia. When shopping, make use of the supports so that if you are living with dementia you can continue to shop if you choose. It is also important to make sure you are in the right frame of mind. With the ever changing labels or packaging on containers, and the frequency at which the stores move items from one area of the store to another, it is important to be ready for the many challenges that shopping presents. Finally, use your time out to connect with others. Bring along a trusted family member or friend for company. Below are strategies when planning to shop, and doing the shopping.

“Would it be easier if they just did the shopping? Sure, but they know how much I still like to be able to do it, and so I only go once a month like to do a large amount of shopping, but I still keep my hands in that way and having [family] go with me now alleviates all of the problems of…not buying something that I should be buying and buying too much of something that I’ve already got at home. So that’s really solved that problem.”

— Person with dementia
planning & making lists

Living with the effects of dementia may make it more important than ever to plan shopping trips beforehand. Shopping at the drop of a hat may be less likely and can cause added stress and confusion. Below are some strategies to help prepare for grocery shopping.

• Create a meal plan before shopping – make a grocery list based on your meal plan.
• Create a list of pantry staples with quantities (e.g., 4 cans of tomatoes, 2 cans of tuna, etc.) – check your pantry for items you are running low on, and add them to your grocery list.
• Create a list of staples that you need to purchase weekly or whenever you do your groceries (e.g., milk, eggs, bread).
• Keep a running list of items to purchase – when you run out of something, add it to the list immediately.
• As a memory aide, cut out current labels on food packages to refer to when making your grocery list.

deciding where to shop

Any store can be overwhelming. Keep with what is familiar and comfortable to you – try to shop at the same store. Below are some strategies when deciding where to shop.

• If you are still driving, take a consistent and familiar route to the store.
• Go to the same store(s) – it can provide a sense of security and also the staff will get to know you over time.
• Avoid large grocery stores; smaller stores may be less overwhelming.
• Shop in strip malls with multiple stores so that you can complete other errands at the same time (e.g., get prescriptions at the pharmacy, pay bills at the bank, get gas, etc.).
deciding when to shop

Due to transportation issues or availability of other family members or friends who provide support, some people may find it more convenient to shop weekly or monthly, whereas others prefer to shop more frequently. Either way, it may be an idea to be consistent and shop on the same day and at the same time. It is also important to shop when you are at your best. Below are some strategies for all situations.

Strategies for shopping more frequently:

- Plan items ahead of time.
- Refer to what’s in the kitchen before deciding what to buy.
- Pick up only a few items at a time.
- Walk through the store for new meal ideas.
- Plan easy to carry shopping loads.

Strategies for shopping less frequently:

- Go routinely (e.g., once a week) for fresh items.
- Ask for help from other family members, friends and staff at stores.
- Keep meals simple and use fewer items.
- Keep a well-stocked pantry and freezer – a lot of stocked items on hand.
- Plan for large infrequent shopping trips.
- Plan transportation for larger trips.
- Use a grocery shopping cart to transport groceries if walking to the store.

pace of shopping

As a result of living with dementia, you may experience changes in your energy level. Consider the following strategies while shopping.
- Be aware of and adapt to daily changes in your energy level – shop when you are at your best and have the most energy.
- Choose a shopping time that is less busy.
- Make fewer stops while out.
- Go shopping when you are not stressed.
- Remember that it’s okay to slow down.
- Shop with someone (preferably the same person) who understands your need to slow down.
- Take frequent breaks – find a quiet area if you become overwhelmed and practice some deep breathing, or just close your eyes for a couple minutes.
- Make sure you have a lot of time; do not rush.
- Give yourself a pat on the back when tasks are accomplished.

**navigating the store**

Most grocery stores today are very large; they generally have aisle product information signs. Below are other strategies to help navigate a grocery store.

- Get to know personnel at the store; plan a route within the grocery store with a member of the staff.
- Some stores will also have staff to accompany and assist you as you do your shopping. Contact your store to see if this is an option.
- Create a grocery list based on the aisles in the store. Some stores may have aisle guides. Contact your store to see if this option is available.
- Go through each aisle of the store one at a time – this may also help if you have forgotten to mark something on your grocery list.
- Consider shopping online. Some grocery stores and pharmacies will do the shopping for you and also deliver your order directly to your home.
planning & preparing meals at home

The second section of this guide is dedicated to planning for, and preparing meals in the home. In the same way that grocery shopping is inevitable, so is planning for and cooking meals. Whether you are planning a menu for a daily meal, or for larger gatherings, there are a lot of decisions to make. The more organized you are, the easier it will be.

planning a meal

Planning a menu or meal plan is a first good step toward organizing daily and weekly meals. As a partner in care, ensure that the meal preferences of the person with dementia are being incorporated. Consider the following strategies.

- Together as a team (person with dementia and care partner), plan ahead and prepare a 7 day menu with 3 meals a day.
- If it is difficult to think of ideas for what to eat, use a recipe book or get support to create a list of meal ideas that you enjoy to provide inspiration. Make sure to post the “Meal Ideas” list where it is most visible; on the fridge is a good option.

“Well we might have to start organizing between her kids and I, you know like a weekend kind of thing, and say ok we’re going to cook today and do a bunch of different things to put in the freezer – you know spaghettis, lasagnas, casseroles whatever that she could then just pull out and put in the microwave. And you know then it meets all the criteria, it’s stuff she likes, it’s home-made, it’s controlled, and then we’ll know too what she’s eating out of the freezer and whether she’s gone up or down in her patterns.”

— Partner in care
• Go online for recipes and menu planner – www.eatrightontario.ca or www.about.com/food.

• Use the meal plan to go grocery shopping.

• Plan your meals so that you can have leftovers for an additional meal the following day. For example, on Monday, cook 2 chicken breasts. Eat one for dinner and save the second to cut up and add to a Caesar salad for lunch on Tuesday.

• Plan for a time when you can cook large batches of food for freezing (e.g., soup, baked goods) – ensure that you add the ingredients for batch cooking to your grocery list.

• Plan for meals and batch cooking based on seasonal availability (e.g., apples, squash, root vegetables).

• Batch cook then freeze in smaller portions.

• Plan to buy and freeze processed/prepared store bought items.

staying organized

Staying organized in the kitchen can help to maintain independence in meal planning and preparation. Below are some organizational strategies to assist you.

• Use labels or photos on cupboards and drawers to make it easier to find essential kitchen tools and food items.

• When you remove an item from a kitchen drawer or cabinet, try to return it to the same location.

• Keep frequently used items in an accessible location – preferably where you can see them.

• Keep items on lower shelves to avoid the potential hazard of falling due to increased possibility of balance issues. Alternatively, invest in kitchen aides (e.g., “the claw”) to help reach items on higher shelves.

• De-clutter your kitchen; get rid of items you do not use and only keep the bare essentials.

• Use timers to keep you organized while cooking.

• Follow a routine with respect to mealtime.
hosting large parties

Having family and friends in your home to share a meal is a great time to socialize and to stay connected. This may not be everyone’s “cup of tea” however. But if you can manage having large gatherings in your home, below are some strategies to help in the planning.

• Keep it simple and informal. For example, have guests get their own drinks.
• Make it about the visit, not about the food.
• When planning the menu consider buying pre-cooked food, or take advantage of frozen casseroles.
• Have the meal catered, order in, or consider having a potluck.
• If you plan to offer a buffet, be prepared to assist the person with dementia through the buffet line. For example, allow them to go first in the line or prepare a plate for them.
• Ask for help and delegate responsibilities. Plan for help to prepare, shop, cook, serve and clean-up. Asking for help during the party will ensure that you can enjoy the party as well!
• Try to have as much work done beforehand (e.g., set table).
• Make a quiet area available if you or your family member with dementia becomes overwhelmed and needs some time to recharge.

managing decision making

Decision making can be tiring and stressful. The individual with dementia may make the decision to shift the responsibility to making decisions in partnership with their partner in care. Meal planning can be overwhelming. By allowing someone else to make key decisions or initiate the process, the partner with dementia can continue to be involved. Consider the following strategies when dealing with decision fatigue.
• Allow others to make mealtime decisions for you based on your preferences.
• Support the decision of the person with dementia.
• Support the partner in care when decision making responsibilities are transferred to them.

independent meal preparation

As previously mentioned, it is important for those living with dementia to continue to participate and engage in preparing meals for as long as it is safe. Whether you are a person with dementia or a partner in care, consider the strategies below to assist in and support independent meal preparation.

Strategies for the person with dementia to successfully prepare meals independently:
• Stick to old favorites and keep meals simple.
• Prepare all ingredients before beginning the cooking process.
• Consider using pre-washed, pre-cut ingredients.
• Set aside ingredients that you have used already.
• Use the slow cooker.
• Ask a friend or contact Community Care Access Centre (CCAC) for support/assistance with meal preparation.
• Prepare meals for a day or two in advance (e.g., cook a pot of soup or stew).

Strategies for partners in care to support the independent meal preparation of persons with dementia:
• Talk with the person with dementia about personal capabilities.
• Encourage early communication in how to adapt to changes, and identify strategies to continue involving the person with dementia in the meal preparation process.
• Discuss how each person can contribute to meal preparation.
• Include the person with dementia, be flexible and allow for meaningful involvement.
• Plan meals for a longer time frame (e.g., 7 day meal plan) and provide assistance to do the shopping and meal planning.

Strategies for working together to prepare meals:
• Assign specific meal preparation tasks (e.g., cutting up vegetables for a salad) and areas to work in.
• Communicate openly when cooking together.
• Be respectful and understanding of each other.
• Support the decision of the person with dementia.
• Provide encouragement.
• Invite partner to sit with you in the kitchen while you work to socialize.

avoid distractions while cooking

Due to changes in memory, it may be more likely that persons with dementia could be distracted while cooking. Below are some strategies to minimize distractions while cooking.
• Make sure you have the time to cook - don’t rush.
• Limit other distractions while cooking:
  o Avoid having the television or radio on, or having other people talking around you.
  o If the phone rings, let it go to voicemail, or turn the phone off before beginning.
  o Consider using call display to quickly screen for important phone calls.
• Follow a recipe and check off steps as you complete each phase of the recipe.
• Assist with meals in steps.
• Have someone read the ingredients as you add them to your recipe.
• Use a timer to remind you when the food is ready, whether it is on the stove or in the oven. Use sticky notes to remind yourself what the timer is for.
• Spend time writing or typing out recipes to refer to.
lack of time & energy for meal preparation & clean-up

Consider how much time you spend making meals every week! With the possibility of energy levels diminishing, you may want to adjust how you approach meal preparation and clean-up. Here are some strategies to consider.

• Be honest! If food preparation and cooking is getting too much, tell someone. Help is easy to get, but often hard to ask for.

• Be resourceful in utilizing a variety of services in your community (e.g., meals on wheels, community centres, legions, churches, culinary college programs).

• Converse with a counsellor about other options in your community.

• Consider buying ‘homemade’ food:
  o ‘Homemade’ food sales may be offered by church groups, farmer’s markets, bakeries, ready-made deli counters, etc. in your community.

• Use leftovers (e.g., use for another day or in another recipe):
  o Ensure that there are leftovers.
  o Use clear containers to store leftovers and label the container with the date it was frozen and what is in the container.
  o Use an item that you prepare in “batch cooking”.

• Purchase frozen dinners to eat occasionally as frozen meals can be high in sodium.

• Have a larger meal at lunch so when energy is low in the evening you can have a lighter meal with less prep and less clean up.

• Avoid preparing complex meals. Instead create simple meals that require few steps.

• Use a dishwasher.
eating in the home

Eating out may not be an option for everyone. Some people have limited transportation, energy or interest. Eating in the home as opposed to in a restaurant is always a more economical option since home is a familiar place, provides comfort, and can be more relaxing than eating out. Further, eating at home provides more opportunity for intimate conversations with family and friends.

when the partner in care is absent from home

If the partner in care is absent during mealtime, works outside the home, or is out of the home for an extended period of time (e.g., holiday, work trip, hospitalization), consider the strategies below.

- Use meal services (e.g., meals on wheels/home food services, day programs) or respite care.
- Have someone check in to ensure the person with dementia has what they need to prepare meals and that they are remembering to eat and take their medications.
- Prepare meals in advance (e.g., batch cooking).
- Use canned goods (e.g., stew, chili, baked beans).
- Use a day minder to assist with food selection and also scheduling and timing of meals.

“…so from one week to another, she (a woman who comes weekly to assist with cooking) doesn’t know how tired my head’s gonna be on that day. And that governs what I can make. So you don’t want to be working on something really that takes a lot of work on a day that my head isn’t there to do it, because that’s not productive either. So I have found that I’m making simpler things now than what I was probably a year ago.”

— Person with dementia
- Use timers to help signal that it is mealtime. Make sure to write a note on the timer to indicate what it is for.
- Invite family members or friends to go to the house to dine with the person with dementia.
- Make arrangements for delivery of a pre-paid meal from a restaurant at a set time.

**skipping meals or eating more than usual**

Skipping meals may not always be intentional. It can be easy to lose track of time, or you can simply forget to eat. Your body may not react the same way to tell you that you are hungry or full. Sometimes, however, there is a lack of motivation to prepare food. Care partners can assist to ensure that meals are timely and nutritious. Below are some strategies to help identify signs of eating too much or too little, or to help regulate food intake.

- Look for signs of over eating or under eating, such as weight loss or weight gain.
- Tracking weight can help to determine if someone is eating well or not. Alternatively, be aware of unusual amounts of food in the refrigerator or cupboard (e.g., too little left uneaten or too much eaten), mood changes (e.g., irritability), and headaches.
- Stick to a routine/schedule – place reminders around the house to help.
- Check to see if medications are being missed or if double dosing is occurring – could be an indication of missing meals or over eating.
- Use a day minder to help regulate food intake.
- Have someone check-in regularly.
- Eating out with someone (at a restaurant) can increase appetite.
eating outside the home

Eating out, either in a restaurant or at the home of another family member or friend, can provide a break for you or your family member from having to plan, prepare and clean-up after a meal. Eating out is a nice treat and can also help to increase the appetite. Although eating outside the home may have been easy in the past, living with dementia may create some challenges for you now. For example, your energy level or the energy level of your family member may be lower than it used to be. Restaurants and the home of friends and other family members may be loud and unfamiliar. Making a decision about what to eat can also be problematic. For persons with dementia, it is important to express to your care partners your interest to eat out and ask them to initiate taking you out from time to time if you want or need a change of routine and scenery. Below are some strategies to deal with these issues and more.

When you experience fatigue or your energy levels are low in the evening, consider the following strategies:

• Plan to go out for dinner earlier in the evening.
• If you have a planned event in the evening with other family members or friends, take a nap in the afternoon so that you are well rested.

If you or your family member find that restaurants are too loud and busy, consider the following strategies:

• Go to a restaurant that is less busy. For example, avoid sports bars that are louder and busier than most, and can be overwhelming because of all the television screens broadcasting various sporting events.

“[My wife] doesn’t have to get it ready or do the dishes or anything – just eat out and somebody else’ll do the clean-up.”

— Person with dementia
• Ask the staff to be seated at a booth or at a table on the outside wall of the restaurant, away from the kitchen. This is usually a better option than sitting at a table in the middle of the restaurant.

• Go out for dinner during off hours.

• Instead of going to a restaurant, go for a meal at the home of another family member or friend.

• Find a quiet place at the restaurant or in the home of another family member or friend to retreat to if you become too tired or over stimulated.

If you have a hard time narrowing down your meal options and making decisions, consider the following strategies:

• Go to a favourite restaurant where you know the menu and perhaps even some of the wait staff.

• Preview online menus and decide what to eat before you go to the restaurant. This way you won’t feel rushed or pressured to make a decision.

• If you have eaten at the restaurant previously, decide what to eat before you go based on your previous experience.

• Write down your favourite meals at different restaurants that you can refer to when you go back.

• Ask your server to give you more time to look at the menu - allowing time for choice.

• Order what a friend or family member orders.

• If you are placing a food order at a counter, wait until you have decided before getting in line, so you don’t feel pressured to make a decision.

• Ask your friend or family member to order for you, while you get a table.
it’s about more than just the food

Although food and mealtime is essential for nurturing the body, it also provides a space for persons with dementia to continue to feel connected to others, as a means of honouring the identities and essence of persons living with dementia and a place where clues could be picked up on the ways that life is evolving and changing that might need to be addressed. Thus, food and mealtimes are not just important for nurturing the body but also important for nurturing the soul and what make us human. Additionally, food and mealtimes can provide an opportunity for social stimulation and a change of scenery. Just the act of being asked out, or to join in a meal, can sometimes be enough. Below are some strategies related to nurturing the soul, including maintaining social connections, making the time count, and engaging in meaningful conversation.

maintaining social connections

- Attend church or community socials, or dine with friends and family.
- Continue to attend gatherings and parties.
  - Know your own limits. Larger groups can be over stimulating and can leave people in the dark/confused and stressed.
  - Give yourself a time limit (e.g., wedding – only go for the ceremony).
  - Find a quiet space to retreat to.
  - Go with a person you are comfortable with and who understands your situation and needs.
- Keeping group size small can allow for more meaningful interactions.

“I just enjoy their company so much...even just to go for a coffee, so it isn’t even the idea of just the food.”

— Person with dementia
• Inform other family members and friends to speak slowly, pause and repeat if necessary.

**taking more time for meals**

• Schedule more time for meals.
• Treat the meal as the main event of the day to connect with family, or a special event during the week.
• Mealtime can be a way for family to see/observe changes and acknowledge difficulties in the progression of the disease.
• Slowing down can increase appetite and improve digestion.

**conversations**

• Be present in the moment during your conversations.
• Allow everyone time to respond and take part in the conversation.
• Don’t transition from one topic of conversation to another too quickly and allow periods of silence so that persons with dementia have time to process and engage in the conversation.
• If you have difficulty starting or maintaining a conversation:
  o Serve food that may have meaning to you or your family member (e.g., a food item that you regularly ate as a youth) and use this memory to generate conversation.
  o During meals, sit beside a window and talk about the scenery.
  o Provide reading to stimulate conversation.
  o Share updates from other family members.
  o Refer to your family memory book before the meal for conversation ideas.
  o Talk about past events or future plans (e.g., trips, visiting family, or outings).
  o Talk about a recent movie, TV program, or sermon you heard.
safety

Below are some safety issues to consider when eating inside or outside the home.

safety in meal preparation at home

- Have a multipurpose fire extinguisher in your kitchen.
- Ensure your home has an adequate number of smoke detectors in case of fire, as well as a carbon monoxide detector.
- Have a first aid kit handy.
- Avoid cooking with hot oil.
- Leave reminders for yourself like “turn off the stove”. Make sure these reminders are placed where you can see them easily.
- Use appliances with auto shut off.
- Use timers routinely.
- Install isolation valves on gas stoves and heaters that turn the equipment off after a period of time.
- If possible, set the hot water system to a ‘safe’ temperature.
- Be cautious when using, storing, or cleaning sharp knives.
- Avoid small rugs in the kitchen.
- Clean spills right away.
- Be cautious when reaching for items high on top shelves – this could pose a falling hazard due to balance problems.
- Store food, utensils, pots and pans on lower shelves.
- Arrange for support when cooking and for regular support in preparing weekly meals.
- As the disease progresses, consider using a toaster oven or microwave, rather than the stove.
safety when shopping or eating in the community (restaurant)

- Take care when touching plates – they can be hot.
- Ensure hot liquids are in the middle of table.
- Take care when using straws – ensure that they are the appropriate size for the glass to avoid eye injuries or spillage.
- Take care when cutlery is rolled in a napkin – sharp knives and forks may cause injuries.
- Be extra careful when in a restaurant with dim lighting.
- If sitting in a raised booth (one step up), take care when stepping up or down.
- The floor in the bar area and near the kitchen may be slippery – be cautious when walking in these areas.
- Use credit or debits cards rather than cash when paying for meals or groceries.
- Use cues to help you remember passwords and PIN numbers on debit and credit cards – do not carry the password or PIN number in your wallet. Alternately, speak with your bank or trust company about PIN free debit and credit cards or chip-bypass procedures.
- Carry small bills if you are paying by cash – it is easier to make change.
- Ask about the possibility of setting up a tab at a familiar or favourite restaurant.
- Shop or eat out with a trusted person for assistance.

“I prefer the smaller store and I prefer the store that everyone knows me. I don’t go to any other grocery store at all, that’s my choice.”

— Person with dementia
endorsement for the guide

As a nutritionist and researcher, I have been working for some time with individuals with dementia and their partners in care on nutrition, eating issues and ways to stay healthy by eating well. For many, this is a daunting task. This new By Us For Us Guide “Food & Mealtimes” provides a host of practical tips and ideas for both the person with dementia and partner in care on everyday concerns about food and eating. Its information on how to shop for groceries, store foods, and prepare and eat meals will encourage continued self-confidence around food and related issues, pleasure in eating, maintaining social contacts over mealtimes and will contribute to well-being for the person with dementia by making food and mealtimes more enjoyable.

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The Food and Mealtime Guide is a stellar tool designed to help those living with memory loss and their care partners. The simplicity and practicality of the guide will make this a must read for persons living with dementia and their family partners in care. The importance of maintaining a good diet is paramount in helping to preserve health. This guide needs to be available to all persons with dementia and their partners in care.

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acknowledgements

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Brenda’s Story
– the inspiration behind the “By Us For Us” series

When Brenda Hounam was diagnosed with Alzheimer’s disease at the age of 53, she realized that very little information was available for persons living with early stage memory loss. The dominant perception was that persons living with memory loss could no longer learn and be involved in their own care. Brenda knew differently. She was inspired to address this gap - to develop a series of resources specifically designed by and for persons with dementia. In 2006, she approached two of her peers with her idea and was astounded by the enthusiasm and support they offered. Through Brenda’s contacts at the Alzheimer Society of Brant, the Alzheimer Society of St. Thomas and the Murray Alzheimer Research and Education Program at the University of Waterloo, Brenda connected with various persons living with dementia from all around Ontario to work on what came to be called, the “By Us For Us” (BUFU) guides. These guides provide tips and strategies for managing daily challenges and enhancing well-being for themselves and others living with memory loss. Since the publication of the first guide, “Memory Workout,” and subsequent guides focussed on issues raised by persons with dementia, the project has evolved to include a guide researched and developed in partnership with persons with dementia and family partners in care, and a series dedicated to the needs of family partners in care. The philosophy of the project remains steadfast - the BUFU series places importance first on the experiences, suggestions, and tips from those directly affected by dementia FOR those directly affected. Brenda has been a true inspiration and role model to her peers and without her determination and perseverance, this project would not exist or have the international recognition that it does.
we welcome your input

If you’ve been diagnosed with early-stage memory loss or are a partner in care and would like to comment on this guide or suggest topics for future guides, please contact MAREP at info@the-ria.ca.

To order additional copies of this guide, contact:

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Permission is granted to make an enlargement of this guide to suit the visual needs of individual readers.

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