

# SUPPORTING DEMENTIA CAREGIVERS: A DECISION-MAKING ROAD MAP

FINANCIAL & LEGAL DOCUMENTS, & UNDERSTANDING YOUR PERSON'S WISHES



DRIVING



WHERE TO



Live?



END OF LIFE CARE



DECISIONS

GETTING A DIAGNOSIS

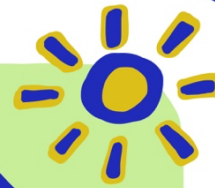


DECISIONS DAY-TO-DAY



TAKING CARE of

YOURSELF



These ARE SOME OF THE **MOST COMMON DECISIONS** CAREGIVERS IN ALBERTA ENCOUNTER, BUT EVERYONE'S JOURNEY IS **UNIQUE**.

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# GETTING A DIAGNOSIS

You can seek a diagnosis through different channels.

EMERGENCY

811

DEMENTIA  
ADVICE  
SERVICE



A HOSPITAL VISIT CAN BE AN OPPORTUNITY TO TALK WITH A GERIATRICIAN.



IT'S OK TO TALK WITH YOUR PERSON'S FAMILY DOCTOR.

I CAN REFER YOU TO A SPECIALIST!



FAMILY DOCTOR

"IT'S IMPORTANT FOR FAMILY MEMBERS TO ATTEND THESE MEETINGS, BECAUSE YOUR PERSON ISN'T ALWAYS GOING TO REMEMBER WHAT WAS SAID, OR THEY CAN'T COMPREHEND IT."



GETTING A DIAGNOSIS

GETTING A DIAGNOSIS CAN TAKE TIME, COURAGE & ADVOCACY

"THIS IS HARD & CAN TAKE TIME, BUT A DIAGNOSIS CAN PROVIDE A POINT OF ENTRY INTO THE HEALTH CARE SYSTEM & ITS RESOURCES & SUPPORTS TO LIVE WELL."



SHARING YOUR CONCERNS, AND/OR A DIAGNOSIS, WITH THOSE CLOSEST TO YOU, CAN GET YOU THE SUPPORT YOU NEED.



**ADVOCATE** FOR THE PERSON WITH DEMENTIA & FOR YOURSELF AS A CAREGIVER.

# FINANCIAL & LEGAL/UNDERSTANDING WISHES

## FINANCIAL & LEGAL DOCUMENTS, & UNDERSTANDING YOUR PERSON'S WISHES




  
**POWER OF ATTORNEY**  
FINANCIAL MATTERS


  
**PERSONAL DIRECTIVE**  
PERSONAL & HEALTH MATTERS

  
**GOALS OF CARE DESIGNATIONS**  
GOALS OF CARE ARE COMPLETED WITH A DOCTOR.



  
YOU DON'T NEED A LAWYER TO COMPLETE A P.D. IN ALBERTA.

"SOMETIMES THE PUBLIC DOESN'T KNOW THE INS AND OUTS OF THOSE GOALS OF CARE DESIGNATIONS!"

  
DO YOU HAVE A CLEAR UNDERSTANDING OF YOUR PERSON'S GOALS & WISHES?

GET FAMILIAR WITH THE FINANCIAL SITUATION!

IT CAN BE HELPFUL TO PUT LIMITS ON CREDIT CARDS.



CONSIDER CREATING JOINT ACCOUNTS



TALK TO THE BANK!

\$\$\$ THERE ARE RESOURCES FOR MANAGING YOUR PERSON'S CARE:

DISABILITY TAX CREDIT \$

ALBERTA AIDS TO DAILY LIVING \$

\$\$\$ HOME CARE: THERE ARE MANY OPTIONS, INCLUDING CLIENT DIRECTED

"[LEGAL DOCUMENTS ARE] VITALLY IMPORTANT TO BEING ABLE TO MAKE ANY DECISIONS FOR THEM & TO GET THEM THE CARE THEY NEED!"



DO YOU HAVE A CLEAR

IT'S THE GREATEST GIFT YOU CAN GIVE YOUR FAMILY BECAUSE IT MAKES THOSE DECISIONS A LITTLE BIT EASIER.

# DRIVING

IS YOUR PERSON'S DRIVING BECOMING UNSAFE?

HAVE THAT HARD & HONEST CONVERSATION!



Seek ALTERNATIVE TRANSPORTATION



CAR ACCIDENTS

Be OBSERVANT OF HOW THEY'RE DRIVING

GETTING LOST ON THE WAY TO FAMILIAR PLACES



"We THOUGHT MAYBE IT WOULD BE BETTER if A DOCTOR TOLD HIM, RATHER THAN US."



OTHER PEOPLE CAN HELP!

• GET A DRIVING ASSESSMENT

• TALK TO → police NON-EMERGENCY LINE

YOUR PERSON'S FAMILY DOCTOR



## DRIVING



"We KNEW ... THAT HE SHOULDN'T BE DRIVING."



"[STOPPING DRIVING] ... FOR THE INDIVIDUAL WITH DEMENTIA ... IT'S A LOSS OF INDEPENDENCE!"



"IT WAS HARD BECAUSE HE WAS SUCH A CAR GUY—BUT IT WAS JUST TOO DANGEROUS."



BEING OPEN WITH

family &

friends can HELP IDENTIFY PROBLEMS SOONER!



use CREATIVE STRATEGIES, SPECIFIC TO YOUR PERSON.



## Be OPEN WITH FAMILY & FRIENDS!

# DECISIONS DAY-TO-DAY

"I AM REALLY GRATEFUL FOR THE TIME I GOT TO SPEND WITH HIM. IT'S TOUGH TO CARE FOR YOUR LOVED ONE. YOU DON'T WANT TO SEE THEM SUFFERING."

MANY SUPPORTS ARE AVAILABLE AFTER YOU HAVE AN OFFICIAL DIAGNOSIS.

- SOCIAL WORKER (LEGAL DOCUMENTS & COMMUNITY SERVICES)
- COMPANION CARE
- RESPIRE CARE (IT CAN BE OVERNIGHT)
- HOME CARE <sup>You CAN Self-refer!</sup>
  - PRIVATE
  - CLIENT-DIRECTED
  - SELF-MANAGED
- DAY PROGRAMS

## Tech CAN HELP!

Use POST-IT NOTES AS REMINDERS

DOOR ALARMS TRACKERS

I.D. BRACELET

VIDEO PHONES

## MEDICATIONS

TALK TO YOUR PHARMACIST OR FAMILY DOCTOR!



TRY BLISTER PACKS!

DON'T SWEAT THE SMALL STUFF!

ASK FOR HELP!

## MANAGING INCONTINENCE

DEVELOP STRATEGIES FOR CLOTHING & PROTECTIVE PRODUCTS

WEAR DARK CLOTHES!

FINANCIAL SUPPORT FROM ALBERTA AIDS TO DAILY LIVING

"ASK OTHERS WHAT THEY'VE DONE!"

"READ AS MUCH AS YOU CAN!"  
"TRUST YOUR GUT!"

CALL 911 if YOUR PERSON GOES MISSING!

# DECISIONS DAY-TO-DAY

## Be prepared TO MAKE MEDICAL DECISIONS

GOALS OF CARE DESIGNATIONS?



PROCEDURES & TREATMENTS e.g.

- MAMMOGRAM
- VACCINATION
- ANTIBIOTICS
- DENTAL CARE

MEALS



PETS



House-keeping



MANAGING THE HOUSEHOLD

CPR?

FALLS?

PREVENTION & REHABILITATION

WHEN TO GO TO THE HOSPITAL?



COMMUNITIES CAN PROVIDE RESPIRE & EMOTIONAL SUPPORT

# TAKING CARE OF YOURSELF

"I THINK HAVING A SUPPORT GROUP IS IMPORTANT. A LOT OF TIMES YOU SACRIFICE YOURSELF TO TAKE CARE OF YOUR LOVED ONE, BUT IF YOU'RE NOT HEALTHY, YOU CAN'T HELP THEM!"

CHECK IN WITH YOURSELF TO ASK "WHERE ARE YOU AT?"



"FIND SOMETHING YOU CAN DO FOR YOURSELF THAT'S OUTSIDE OF THE CAREGIVING."



THINK AHEAD = KNOW WHAT'S YOUR "LINE IN THE SAND" THAT MEANS THIS IS MORE THAN YOU CAN HANDLE?



You deserve to get enough sleep!



IT'S OK TO FEEL...

FRUSTRATED

GUILTY

HELPLESS

ANGRY

ISOLATED

OVERWHELMED

STRESSED

TIRED

UNCERTAIN

SADNESS, EVEN WHEN THINGS ARE GOING SMOOTHLY (ANTICIPATORY GRIEF)

A SENSE OF LOSS OR GRIEF, EVEN IF YOUR PERSON IS PHYSICALLY WITH YOU

DECISIONS CAN BE EMOTIONAL.



"DEVELOP A GROUP OF FRIENDS YOU CAN RELY ON!"



DRAW UPON THE SUPPORT OF:

- COMPANION CARE
- FAMILY + FRIENDS
- SOCIAL WORKERS
- ORGANIZATIONS
- FAITH OR CULTURAL COMMUNITIES
- RESPIRE

"THESE ARE HARD THINGS & THEN YOU BLAME YOURSELF. WE NEED TO REMEMBER TO CUT OURSELVES SOME SLACK."

TAKING CARE OF

YOURSELF



TAKE ALL THE HELP YOU CAN GET!

# WHERE TO LIVE?

MANY THINGS FACTOR INTO THIS DECISION, & IT MAY CHANGE ALONG THE WAY.

IT'S OK TO FEEL HELPLESS, GUILTY, OVERWHELMED, HEARTBROKEN, PAIN, RELIEF.

DECIDE ON YOUR STRATEGY BASED ON YOUR OWN PERSONAL SUPPORT NETWORK & SITUATION.



## Home



Home CARE  
Home ADAPTATIONS & TECHNOLOGY  
PRIVATE CAREGIVERS  
Respite

## PLACEMENT OUTSIDE of HOME



LOCATION - CLOSE TO FAMILY + FRIENDS?

WHAT LEVEL of CARE is AVAILABLE?

PUBLIC OR PRIVATE?

COST?

WAIT LISTS?

RATIO of STAFF TO RESIDENTS?

"I STILL FEEL GUILTY THAT I DIDN'T KEEP HIM HOME LONGER. BUT THERE'S NOT MUCH POINT IN FEELING GUILTY... I DID WHAT I HAD TO DO."

"IT WASN'T HOME, BUT IT WAS THE NEXT BEST THING."

## WHERE TO



## Live?



## ASK QUESTIONS!

FAMILY & FRIENDS  
SOCIAL WORKER  
RESIDENTS & FAMILIES AT FACILITIES

Home CARE NURSES

SUPPORT GROUPS

TRANSITION SERVICES

DEMENTIA CARE NAVIGATORS



### THINK ABOUT WHAT'S BEST FOR YOUR PERSON & YOURSELF.

# END OF LIFE CARE DECISIONS

THINK ABOUT YOUR PREVIOUS CONVERSATIONS WITH YOUR PERSON ABOUT THEIR GOALS & THEIR PERSONAL DIRECTIVE.

YOU MAY NEED TO MAKE DECISIONS ON:

RESUSCITATION

COMFORT CARE

GOING TO THE HOSPITAL

IF YOUR PERSON HAS PNEUMONIA OR IS ASPIRATING

NUTRITION & HYDRATION

ASK YOUR HEALTH CARE TEAM ABOUT DECISIONS YOU MIGHT HAVE TO MAKE.

SUPPORTS ARE AVAILABLE!

COMMUNITY

FAMILY & FRIENDS

GRIEF PROGRAMS

CAREGIVER SUPPORT GROUPS

FAITH & SPIRITUAL CARE

SOCIAL WORKER

ASK ABOUT PALLIATIVE CARE.

CONSIDER:  
SERVICE  
MEMORIAL  
OBITUARY

END OF LIFE CARE



DECISIONS

"I NEVER THOUGHT I WOULD HAVE TO STAND THERE & MAKE THAT DECISION."

"Life is valuable, BUT THERE'S VALUE IN A GOOD PEACEFUL DEATH TOO."

EVERYONE'S JOURNEY IS UNIQUE.