## A Toolkit for Patient's and Care Partner's



## **Progression of Disease**

Being prepared to care for a loved one nearing the end of life can be challenging, there are resources available.

- Understanding the different services available and which agencies provide your main sources of support is critical to ensuring you or your loved one receives the best care. (Please refer to the <u>Navigating the System</u> section below).
  - https://www.virtualhospice.ca/en\_US/Main+Site+Navigation/Home/Support/Resources
     /Books +Links +and+More/Caregiver+and+caregiving/Books/A+Caregiver s+Guide +A
     +Handbook+About+End of Life+Care.aspx

It is Important to understand that disease progresses in stages and that these stages may flow into one another, with some stages advancing quicker than others.

- Advocacy is important throughout all stages
- Each stage may bring unique physical, mental, emotional and spiritual challenges
- Ask for reevaluation of supports to keep up with changing needs
- The care team will adjust treatment plans as needed

Waiting Room Revolution Resources

The Waiting Room Revolution Resources Web Page

(<a href="https://www.waitingroomrevolution.com/resources-page">https://www.waitingroomrevolution.com/resources-page</a>)offers free downloadable tools to support patients, families, and healthcare providers dealing with serious illness including:

- Roadmaps for illnesses like\_ALS, Alzheimer's, COPD, and Ovarian Cancer (in English & French)
- Seven Keys One-Pager to help patients and providers feel more empowered
- Health Canada Tools with key questions to improve communication
- Book Club Guide for Hope for the Best

Providing care or being cared for in your home brings additional considerations:

Your caregivers will support you with care, including personal hygiene (toileting, managing incontinence), giving medications and other possible caregiving duties.

Understanding that care plans may not always work out as planned – service providers such as personal support workers may be scheduled at specific times but may be late or unable to attend due to unforeseen circumstances. While this is challenging, it is a reality of care at home.

## Sarnia-Lambton ONTARIO HEALTH TEAM

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Be your own advocate – or advocate for the person you are caring for – you are there to advocate for the best possible care for yourself / the person with the serious illness.



Private pay options are available to augment services provided through Ontario Health at Home (publicly funded resources).

Private insurance coverage may also be an option to help augment supports. Some homemaking services (housekeeping, laundry, outdoor maintenance, food services) have additional costs.

Links to many of these services can be found on AgeFriendlySarniaLambton.ca