ACT
for Parkinson's

Booklet For
PATIENTS & CAREPARTNERS

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Welcome to the
ACT for Parkinson's Program!

ACT stands for **Advanced Care Team**. We are a **multidisciplinary team**focused on treating complex needs. Specifically in the families affected by Parkinson's disease (PD), multiple system atrophy (MSA), progressive supra- nuclear palsy (PSP), Lewy body dementia (LBD) and corticobasal syndrome (CBS).

What is Advanced Care?

Advanced Care aims to support people who had a progression in their symptoms. You may be having more difficulty doing daily tasks, and needing more help than you used to. Our goal is to learn what **your strengths and struggles** are so that we can **help you** fill in the gaps. We want to give you **control and choice** in how you want to **improve your well-being.** We will provide advice and support for you and your carepartners.

As time goes on, new needs and concerns may develop.
ACT is here to help you prepare and to support you through these changes.

OUR GOAL

Our goal is to support you and your family with better management of your complex symptoms and needs. Our hope is to assist you physically, socially, mentally and spiritually. We want to help you live well and have peace of mind now and for what lies ahead. Out expected outcome is quality of life during the late stages of your disease.

How does the Program Work?

The program works by providing integral care to the person with Parkinson and their support system, including family and surrounding community. It will be additional to your current care, not replace your healthcare providers. The multidisciplinary team will assist you to identify your most pressing concerns and will help you work to alleviate or provide resources to address them.

What to Expect?

You will be referred by your neurologist to our team. We will reach out to assess your current concerns and make an appointment to come to the clinic or be seen virtually. On the day of your appointment, you and your carepartners will see the **whole team!** Your needs and concerns will be addressed for approximately 2 hours. Follow-up calls will be arranged, and you will be seen again by the team every 3 months.

OUR TEAM

Neurology

Veronica Bruno, MD, MPH

Clinical Neurosciences, Cumming School of Medicine, University of Calgary.

Dr. Veronica Bruno is a neurologist with a subspecialty in movement disorders. She received her medical degree and neurology residency in Buenos Aires, Argentina. She completed her fellowship in Movement Disorders at the University of Toronto and a Master of Public Health degree at the Harvard TH Chan School of Public Health. Dr. Bruno's primary interest is the treatment of advanced Parkinson's disease, with a particular research interest in the non-motor symptoms of the disease. Such as pain, anxiety, depression, and sexual dysfunction among others.

Nursing

Ellen McRae, RN, BHSc, BN

Clinical Neurosciences, Cumming School of Medicine, University of Calgary.

Ellen McRae is a Registered Nurse at The Salvation Army Agape Hospice with seven years of experience providing palliative care. Specialising in end-of-life care, Ellen uses her experience to help provide dignity and respect in the end-of-life process. By focusing on holistic comfort care, Ellen has been able to put her Bachelor of Nursing at the University of Calgary and Bachelor of Health Sciences at Western University to good use. She is passionate about educating families and promoting her clients' autonomy. It's the joy of providing families and their loved one's peace of mind that keeps her passionate about her job. When she's not at work, Ellen enjoys sipping coffee with her husband, singing and baking. But if you want to get her talking, just ask about her three kids.

OUR TEAM

Psychology

Kristina Waldmann, **MSc, Registered Provisional Psychologist**

Registered Provisional Psychologist, Clinical Neurosciences, Cumming School of Medicine, University of Calgary

Kristina earned a Master of Science in Counselling Psychology from the University of Calgary and is a Registered Provisional Psychologist. She is a Research Associate with the University of Calgary, Clinical Neurosciences. Kristina has had the privilege of working in the mental health field for more than 15 years in a variety of research and clinical roles. She is passionate about advocating for mental health care and her research interests focus on promoting mental health outcomes and reducing stigma associated with mental illness. She is excited to be part of a team that is seeking to improve the healthcare experiences of patients and their carepartners. Outside of work, Kristina enjoys a wide variety of podcasts and finds fulfillment in connecting with others.

Community Liaison

Community Liaison, Clinical Neurosciences, Cumming School of Medicine, University of Calgary.

The Community Liaison for the ACT for Parkinson's program is essential in creating a strong connection between patients, healthcare providers, and their families. They act as advocates for individuals with Parkinson’s disease, helping them access critical resources, services, and support. The liaison works closely with interdisciplinary care teams to ensure that communication flows effectively and that care is well-coordinated. They guide care partners, offering both practical and emotional support, while also helping families navigate the complexities of medical care, insurance, and community services. Additionally, plays a vital role in improving patient outcomes by ensuring that individualized, patient-centred care plans are implemented and that the diverse needs of patients are met throughout their care journey. Through collaboration, education, and resource coordination, they enhance the overall quality of life for people living with Parkinson’s.

OUR TEAM

Spiritual Counseling

Rabbi Rick Kline, MJS, MBA, LLB, BA

Certified Spiritual Health Practitioner, Research Associate, Clinical Neurosciences, Cumming School of Medicine, University of Calgary.

Rick was recruited from the Foothills Medical Center, where he worked as a Spiritual Health Practitioner/Chaplain (SHP) as part of the Palliative Care Team. He was trained at the Brigham and Women's Hospital in Boston. He worked alongside people with dementia at the Bethany Seniors. There he helped to develop and implement a "Dying with Dignity Program". Rick is currently the SHP for the Mineral Springs Hospital and St. Martha's Long-Term Care facility in Banff. Rabbi Rick was ordained at Hebrew College in Boston and received a Master in Jewish Studies. Rick studied Care for the Dying, Buddhist Training and Practice, at Harvard Divinity School. Rick is trained and certified in several healing arts: Yoga, Meditation, Reiki, Johreiand Indigenous Smudging. He previously practiced as a lawyer, then owned and operated two junior oil and gas companies and an innovative power generation company. Rick is an avid bicyclist, skier, hiker, meditator and grandfather.

Research

Karla Cantu-Flores MD, PMD

Research Assistant, Clinical Neurosciences, Cumming School of Medicine, University of Calgary.

Karla is a Research Assistant at the University of Calgary. She is an eager researcher with 9 years of conducting projects to understand neuropsychiatric disorders and disease epidemiology. She is also a passionate medical doctor and paramedic with 7 years of clinical experience in Mexico. Where she has practiced at a Palliative Care centre with a multidisciplinary team. Dr. Cantu Flores is seeking to interconnect people's neurological and mental health needs with scientific and technology research. She uses that experience to promote quality of life and empowerment of patients and partners.

Neurology

What is the Neurologist's Role in ACT for Parkinson's?

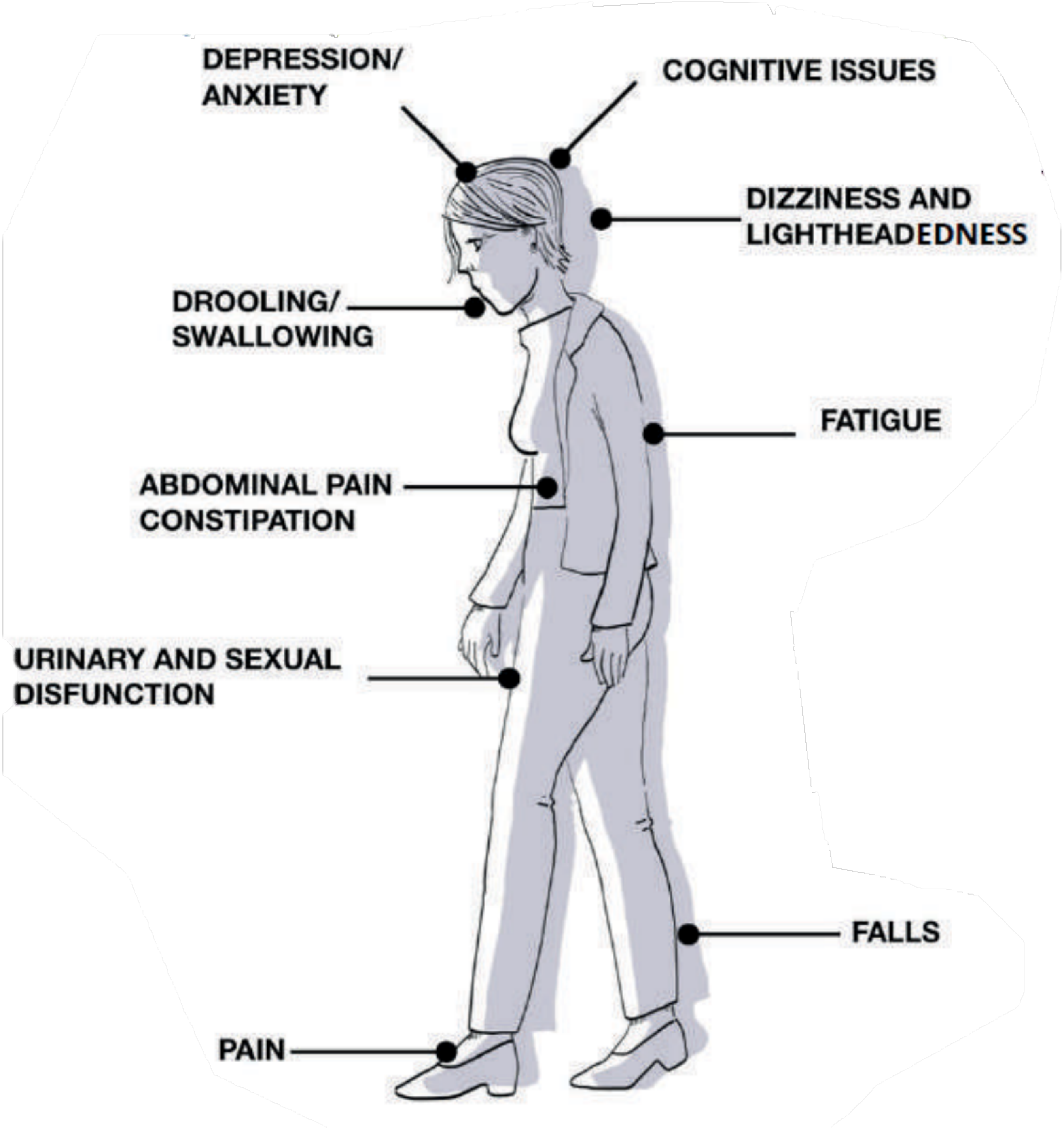
The neurologist's role in the team is to evaluate your motor and non-motor symptoms. It will focus on the non-motor symptoms of the disease, to alleviate your most important concerns. There are some aspects that you may be familiar with already from your primary neurologist. The main goals of the advanced care neurologist are to improve your quality of life and provide comfort and support.

What to Expect?

People with Parkinsonian syndromes, carepartners and their family members will be given the necessary advice:

- Progression of Parkinsonian syndromes.
- Possible adverse effects of medications for Parkinsonian syndromes
- Advance care planning, including orders for advanced decisions for choosing specific treatments.
- Options for future management

Some of the symptoms we can help with are:



Nursing

What is the Nurse’s role in the advanced care team for Parkinson’s?

The nurse’s role is to assess the needs of you and your family and to coordinate care. The goal is to promote quality of life and comfort amid chronic and progressive disease.

The nurse will help to streamline your care by improving team coordination. She will promote communication between you and the ACT for Parkinson’s team. She will help by assigning tasks to the team based on your needs.

The nurse will strive for the best patient experience possible. We aim to empower you with education and enhance your ability to cope with ever-changing symptoms.

The nurse will be a part of initial assessments, education and ongoing follow-ups.

For the person living with parkisonism

The nurse will do a thorough assessment of your current needs. The focus will be on non-motor symptoms, the ability to do daily tasks, and promoting comfort. Education will be provided about ongoing care, symptomatic red flags, and self-management.

Expect comprehensive assessments addressing physical, social, spiritual, and psychological needs. The nurse will hear your concerns and advocate for you to ensure the team addresses your current and future needs.

For the carepartner

The nurse will assess how you are coping and how we can better use the strengths and resources you have.

Expect the nurse to counsel, validate, and inform. We are on your team and will advocate for you and the person you care for. The goal is to help you have peace and feel supported in whatever decisions you and your family makes.

Red Flags

We will support you but sometimes you may need urgent care. We identify those situations as red flags, and they are:

Pain - Sudden increase or new pain that is not alleviated or lessened by current medicinal and alternative therapies.

Hallucinations- seeing or hearing something that isn't there. Can be frightening or not, some commonly seen hallucinations are a person who isn't there, bugs or small animals.

Fever - A temperature of 38°C (100°F) or higher that does not improve with tylenol or cooling techniques (cool bath, fan, lighter clothes etc.).

Urinary Tract Infection - If you have pain or burning when peeing, need to pee more often than usual, the pee looks cloudy, dark or has a strong smell, or if you're needing to pee suddenly or more urgently than usual.

Constipation (severe) - Unable to have a bowel movement for 3 days or more, lower abdominal pain, bloating, nausea, loss of appetite, feel the need to defecate without being able to, no longer passing gas, straining or feeling like there is a blockage.

Choking - Coughing after eating/drinking, clutching at the throat, inability to speak, breathe or swallow, wheezing/unusual breath sounds, gagging, face red, lips blue.

Falls/Dizziness - If you fall, or fall more often, this is a cause for concern and should be followed up with

When red flags appear contact your primary care provider or Call ▸▸▸▸▸▸▸▸▸▸▸▸▸▸▸

Psychology

What is the Psychological care ACT for Parkinson's?

Psychological care refers to receiving support for mental health and well-being. This may include support for relationships, self, and/or management of psychological symptoms.

Holistic care is meant to be a complement to the care and support that are already established. Working from this perspective, healing involves nurturing the mind, the body, and the spirit, of the person as well as their support system. To quote George Eliot, "What do we live for, if it is not to make life less difficult for each other?"

For the person living with parkisonism

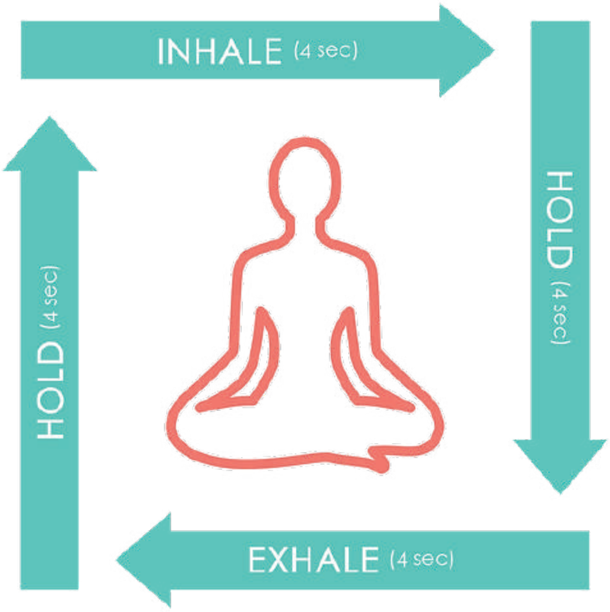
We will address aspects that may include emotion regulation, increasing feelings of being valued, supporting participation in your family life, and/or distress tolerance. Therapeutic success begins with trust, connection, and understanding. Our practice draws from Mindfulness and Dialectical Behaviour Therapy (DBT) emphasizing a collaborative approach. Our goal is to hold space for each person's journey without judgement.

For the Carepartner

For carepartners, we will provide psychological support that can range from emotion regulation and stress management to relational issues, trauma, and grief. We enjoy working with goals in mind, celebrating the successes each individual has made along the way, and understanding when our work together comes to an end. We work with individuals to nurture self-awareness, set the foundation for skills, and build resilience to create sustainable change.

Kristina's quick tip

Tremors can temporarily worsen during periods of anxiety, stress and fatigue. Relaxation strategies can help. A gentle reminder to breathe deeply. Like square breathing.



Community Liaison

The Community Liaison empowers participants to access community resources. We will assist participants and family members to improve their well-being by identifying their needs. Then we will work with you to access community resources that will promote comfortable and peaceful living.

For the person living with parkisonism

The community liaison will work with you to discover your goals and needs. We will find what supports will work best for you and your family. We can assist with homecare, transportation, mental health support systems, financial aid and more. The community liaison will assist in identifying physical and emotional safety at home to ensure the patient can access proper interventions. Expect the communi- ty liaison to promote autonomy and comfortable living. The goal is to support youand minimize stressors. We want to help ease your challenges and assist with day-to-day living.

For the carepartner

The community liaison will ensure you feel confident caring for your others and yourself. We can assist with addressing many obstacles and help you connect with the right community support systems.

At ACT for Parkinson’s, the goal for community liaison is to ensure the carepartner has proper resources and assistance available. We will work collaboratively to make sure needs are being met and potentially identify concerns in order to connect them to the appropriate resources.

Quick tip!

Expand your team: You are not alone! Calgary has an abundance of resources that can help improve your life and positively impact you and your family. Consider and explore the various local support systems to expand your team and gather additional assistance.

Spiritual Care

What is Spiritual Care in ACT for Parkinson's?

Spirituality concerns connectedness and relationships. It is about how we connect and relate to ourselves, our close family, extended family, friends, community, society, nature or to something greater than us - like God, the Sacred or the Universe. Spirituality is a dynamic and intrinsic aspect of our humanity through which we seek meaning, purpose and transcendence. Spirituality is expressed through beliefs, values, culture, traditions and practices.

What to expect?

Our model of care recognizes that physical, emotional and spiritual beings are intricately connected and when one of these is out of balance, it will affect the other two. Spiritual Health Practitioners are trained to support both emotional and spiritual health.

The spiritual needs of family members may differ from those of the individual and are recognized and supported. Spirituality is integral to coping with serious illness and is provided in a developmentally appropriate manner.

ACT for Parkinson's will serve you and your family in a manner that respects your beliefs and practices. If you prefer not to receive spiritual support, we will respect that as well.

The spiritual health practitioner will ask you about your spiritual beliefs, history and current practices. A spiritual history will identify person preferences and values that may affect medical decision-making.

Spiritual Health Practitioners provide non-judgmental listening and trauma informed care. We use gentle guiding questions to assist you in your processing.

Spiritual Health Practitioner will help you to explore:

- Sources of strength and support
- Coping skills, resiliency and impact of illness
- Questions of hope, values, fears, meaning and purpose
- Struggles with faith
- End-of-life support, grief and bereavement

Rick's quick tip!

If you feel you need assistance to help you cope, heal, relax, open your heart or be inspired, you can ask Spiritual Care to provide you with meditations, relaxation exercises, visualizations, prayers, blessings, sacred/spiritual practices or readings. Just ask!

Advanced Planning Resources

Advance planning is beneficial for every adult. This is why it is recommended to have a Will, an Enduring Power of Attorney and a Personal Directive. These documents should be reviewed routinely and with any changes in health.

1. Will

A will sets out your wishes for your property, possessions and assets for after you die. Executor/Trustee: This person will look after your property, sell it and then distribute the proceeds to your Beneficiaries named in the will. In the event you set up a Trust for dependants, then you will need to appoint a Trustee as well.
The Executor/Trustee should be someone who is close to you and you trust. Alternatively, you can name a financial institution to look after your estate.

2. Enduring Power of Attorney “EPOA”

The EPOA allows someone of your choosing to act as your attorney, in order to deal with your legal and financial obligations. It grants them access to your banking and government records. The EPOA will either be effective immediately or can be enacted once you become unable to make your own decisions.

3. Personal Directive

Provides for the following wishes: · Appointing your Agent, the person you want to make your health related decisions if you become unable to do so. · The kind of medical treatment you want or don’t want, like whether to be resuscitated or not. · How comfortable you want to be. · How you want people to treat you. · When staying at home is no longer feasible, where you want to go and the level of care you would like to receive. What you want your loved ones to know, such as End of Life wishes.

Research

This program runs to support research in the field of Advanced care for Parkinsonism

Why is it important to do research on this topic?

Advanced care research has an essential role in helping evidence-based clinical practice. Unfortunately, current information is limited. Also, it helps in creating services, building educational models and policies, and enhancing communication.

Understanding individual and family experiences can help us recognize the needs in healthcare. By being part of this research, you can expand the benefits to larger communities.

You can be part of a big change!

Quality of Life.

We need research to improve the health system's quality of care. We can do this by learning how to better manage symptoms. Improving our understanding of our patient's wishes and desires can result in better outcomes to help you have a better quality of life

Empowerment

Empowerment is important in health and social care as it gives a greater understanding of how to navigate the healthcare system. When empowered, individuals can confidently ask for the information they need, they can develop their self-awareness and become equal partners in their care. That is why wewant to promote education and training support to empower and fulfil people with parkinsonism and care partners' needs. As well as to measure and identify the best ways of doing it.

Identifying gaps and needs

Patient and family satisfaction is an important indicator for measuring the quality of health care. Because it affects clinical outcomes and promotes the timely, efficient, and patient-centred delivery of care.

Consequently, we want to understand what the most important things are for you. Especially when receiving treatment and support from healthcare facilities.

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