

Let's Talk about Parkinson's: Educational Conference
Friday 24th March 2023
Keynote: Marie-Louise Coleiro Preca
10 mins

Good morning, Veronica Clark, Anne Fribbens, Rodianne Micallef Cann and your respective teams,
Dear friends,

I would like to start by commending Malta Parkinson's and the Nursing Services Directorate for their collaboration in the organisation of this much-needed conference.

I am convinced that your discussions and deliberations today, will be an inspiring experience for all of you.

I am sure that this experience will enable you to continue to strive for a better life for all those that are experiencing Parkinson's Disease, and their loved ones.

I also would like to welcome Anne Fribbens, from the United Kingdom, who is a Clinical Nurse Specialist in Parkinson's Disease, who will be sharing her expertise with us today.

Dear Anne, I am pleased you are here with us today. I am sure that your experience and expertise will bring much added value to the discussions. I am also very pleased that I have this opportunity to meet you again, after quite some time.

I do hope that your visit to Malta, will also give you the opportunity to find some time to enjoy yourself and our unique heritage.

We are informed that Parkinson's is the second most common neuro-degenerative disease in the over 60s, but people may have it for up to a decade before it is diagnosed.

According to the World Health Organisation, globally, disability and death due to Parkinson's Disease are increasing faster than for any other neurological disorder.

In fact, the World Health Organisation estimates that the prevalence of Parkinson's Disease has doubled in the past 25 years, bringing total global estimates to over 8.5 million individuals in 2019.

Recent data shows us that in Malta, there are around 1400 people known to live with this condition.

We must act to try and halt this upward trend, before it gets much worse.

Parkinson's disease is a chronic, progressive disorder that causes one to experience certain physical and cognitive symptoms. These changes can weaken one's ability to control their movements, speak, and complete daily tasks. There is no cure for Parkinson's disease yet,

however most people with Parkinson's can have a normal or near-normal life expectancy. Modern medications and treatments mean that people can manage their symptoms and reduce the occurrence or severity of complications which might otherwise be fatal.

Research is also suggesting that stressful life events may increase the risk of Parkinson's disease. In addition, studies indicate that stress damages dopamine cells, resulting in more severe parkinson's symptoms. It is said that acute stress can worsen motor symptoms.

However, I believe that it is not all doom and gloom, there is much that can be done, including putting policies in place, providing effective, timely and responsive diagnosis, treatment and care, implementing strategies for promotion and prevention, fostering research and innovation, and strengthening information systems.

Surely no one alone can bring about the much-needed change.

We need intersectoral collaboration that brings together policymakers, health-care providers, researchers, and health promotion specialists, in order, to face this growing challenge.

We need also to involve people with Parkinson's Disease and their carers whether formal or informal, to participate in the development of a strategy, plan, and subsequent policies.

That is why I am so pleased that Malta Parkinson's and the Nursing Directorate, which is a government entity, are collaborating, in an interdisciplinary approach to raise awareness of Parkinson's Disease among health professionals and the public alike.

Being a believer of collaboration, I would like to encourage you to keep alive this collaboration and further strengthen it, not only between your entities, but also by building a network of other relevant stakeholders to forge ahead with a vision, strategy, and a national action plan.

From my very own experience, the effect of the work we do collectively for the benefit of others, results in much greater and more effective outcomes and impact, than when we work alone.

I am informed that the care of people with Parkinson's differs from other neurological conditions and more education is needed on how to manage aspects such as medications, multidisciplinary care, and the different stages of Parkinson's.

As a non-governmental organisation, I encourage you to advocate with the authorities and policymakers to build the capacity of trained healthcare professionals, social workers, rehabilitation, and palliative care, including specialist care, in relation to Parkinson's Disease.

I would like to encourage you to raise awareness of the disease with the public in general, so that more people would respond at an earlier stage, to have a better chance of managing the disease.

Likewise, I encourage you to promote educational awareness raising programmes within the interdisciplinary health and rehabilitation workforce and create networks together with other civil society organisations.

According to the findings of a survey conducted by the European Parkinson's Disease Association (EPDA), many Parkinson's patients across Europe are missing out on regular specialist advice in treating their condition.

We therefore need to ensure that equitable care and opportunities, are effectively accessible to all those suffering from Parkinson's. It is important that all Parkinson's sufferers have equitable access to the highest standards of treatment, support and care they need to live a full and comfortable life.

In the process we must not forget the families, as they too need to be supported.

We must ensure that people with Parkinson's, their families and caregivers have the right information at the right time to help manage their treatment, care, and wellbeing.

Unfortunately, Parkinson's sufferers used to feel isolated and excluded from the rest of society.

This is where organisations like the Malta Parkinson's can be of invaluable support to people with Parkinson's by creating safe spaces for its members, providing activities that enhance their daily life experience, and offer support to families and loved ones.

I am pleased to note, that as an organisation, Malta Parkinson's, in collaboration with the healthcare authorities, are doing invaluable work to foster more awareness about this condition.

It is heart-warming that you are providing the family members and carers the moral and psychological support they need to be more resilient in the face of these great challenges in their lives.

Although we all know and share the importance of quality medical care, unfortunately there are still few people who recognise the need for psychological and social support, so that a person can be effectively supported and live better.

I therefore encourage you to lobby for more psychosocial care for people with Parkinson's Disease, and that it should be considered as part of the essential help offered to everyone who needs it, including the family members who live with people suffering from Parkinson's.

There is a need that as a society, we acknowledge and appreciate the contribution and the challenges, that family members face due to lack of resources and support.

From first hand conversations that I have had with relatives and non-formal carers of people with Parkinson's, they tell me how much they are misunderstood and how desolate they feel in the challenges they face.

We need, to appreciate, much more the contribution of relatives, of people with Parkinson's. We must perceive the contribution of

these people, not only from a family perspective, but we must acknowledge that their care for family members, is an invaluable contribution to the country.

I also would like to take the opportunity to continue to encourage everyone, to unite, as one people, to help in the way we can, to ensure, that every member of our society, can live a dignified life.

We must always remember that each and everyone deserves dignity and quality of life. We also must acknowledge the responsibility that each and everyone to safeguard the rights of people with Parkinson's.

We need to ensure that every member of our society enjoys meaningful and holistic well-being.

I augur you a successful conference and look forward to being informed of the outcomes.