

SUPPORTING PATIENTS WITH LIFE LIMITING NEUROLOGICAL ILLNESS IN A PANDEMIC: **SERVICE EVOLUTION**



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Background

Patients with progressive neurological illness are recognised as having palliative care needs with some benefitting from specialist support. The pandemic brought opportunities to develop our service in order that it remained relevant and accessible.

Aims

To identify and reflect on how the Covid 19 pandemic influenced the further development of a Neuropalliative Care service and the factors that ensure its sustainability.

Methods

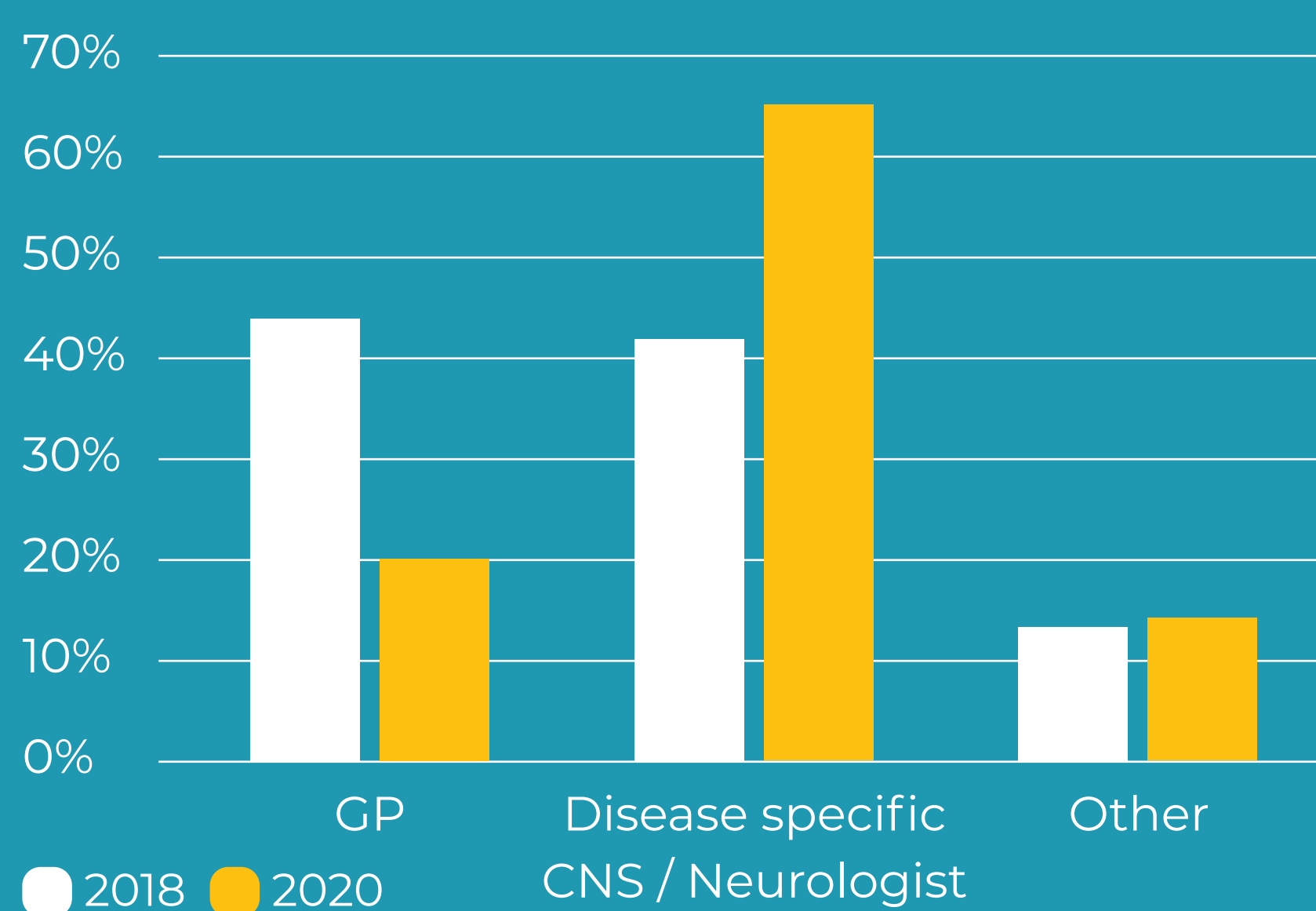
Referrals made to the Palliative Care service for people with progressive neurological illness were reviewed. Referrals received during 2018 (pre-pandemic) and 2020 (mid-pandemic) were extracted from electronic notes and demographic details including age, sex and diagnosis, source and reason for referral were identified.

Results

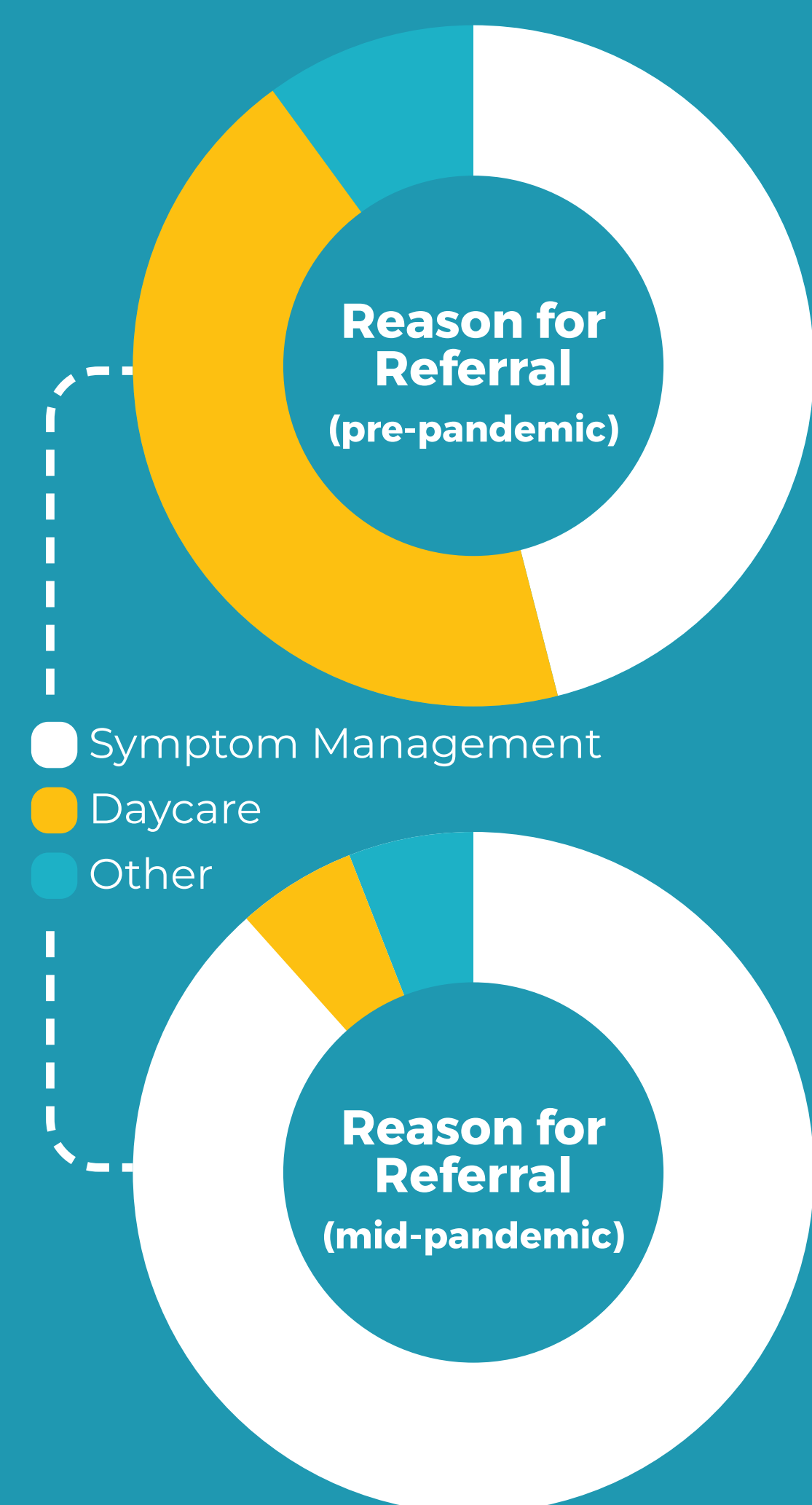
During 2020, 49 patients were referred to the service (an increase of 36% compared to pre-pandemic). 28 (57%) were males, 21 (43%) were females. The age range of those referred was 19 to 83 years (mean = 60 years). 19 patients (39%) had MS with MND being the second most common diagnosis (11 patients (24%)).

During the pandemic, 65% of referrals were made by disease specific CNSs and Neurologists (compared to 42% pre-pandemic). The number of referrals made by GPs reduced during the pandemic from 44% to 20%.

Results (continued)



Prior to the pandemic, 42% of referrals were for Daycare and 47% for Symptom management however, during the pandemic, the majority of referrals (88%) were for support with symptom management. Within this, symptoms crossed physical, social, psychological and spiritual domains and included pain, breathlessness, muscle spasms, carer fatigue and patient distress.



Discussion

Based upon these findings the factors that influenced the changes in our service were identified as being patient-driven or service-driven or an overlap of these two factors.

01 Patient-driven factors

- Need to shield
- Patient not offered or deciding not to start treatments due to risk of immunosuppression
- Patients experiencing low mood and subtle changes missed due to lack of contact with loved ones
- Increased Carer burden due to loss of Respite services

02 Overlapping factors

- Limitations in aerosol generating procedures offered (eg NIV)
- Elective procedures cancelled (eg PEGs)
- Changes in access and accessibility to GPs
- Temporary closure of Respite and Support services, including Hospice Daycare programme

03 Service-driven factors

- Redeployment of disease specific Neurology nurses
- Redeployment of specialist AHP teams
- Rapid adoption of technology enabling commencement of a monthly MDT across Neurology, Hospice and Complex Care services
- Hospice able to offer Home visits throughout pandemic
- As an independent Hospice, had flexibility to adapt and provide services most in need

Conclusion

Our existing service changed throughout the pandemic. Developing relationships with our Neurology colleagues enabled us to collaborate more effectively and set up monthly MDT meetings. We were able to adapt our service based upon the changing needs of our patients and colleagues by ensuring our referral criteria allowed us to consider the individual needs of the patient within the context of what other services were available to them at that time. We are now looking at ways that we can develop and continue to provide a responsive, accessible and sustainable service based on the needs of patients and colleagues.