Providing tailored information and support through the Myeloma UK, Myeloma Infoline and Ask The Nurse services during the COVID-19 pandemic

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1 | BACKGROUND

Patients with haematological cancers, including myeloma (a rare type of blood cancer), are more susceptible to infection than the general population. The UK Government defined patients with blood cancers as clinically extremely vulnerable to COVID-19. In response, third sector organizations with a focus on blood cancers have continued to respond to the crisis by ensuring their service provision is led by the latest research and Government guidance. Providing high quality information and support services in the current climate offers a significant challenge as the information landscape and evidence-base changes rapidly. Myeloma UK has adopted changes to service delivery, particularly on our bespoke Myeloma Infoline helpline and Ask The Nurse (ATN) email services, to ensure they can meet increased demand for tailored information and support whilst keeping abreast of the latest advice. This letter describes the vital role the Myeloma Infoline and ATN services have played in supporting service users to better understand the guidelines, how to apply them to their own lives, whilst considering how these may impact their personal preferences and priorities.

Myeloma UK is the only organisation in the UK to focus specifically on myeloma and related conditions (including MGUS, smouldering myeloma, and AL amyloidosis). The organization has played a pivotal role in research and clinical practise; patient and healthcare advocacy; and, patient and family services for over two decades. Service users engaging with the award-winning and quality accredited Myeloma Infoline and Ask The Nurse (ATN) services typically contact the highly trained and knowledgeable Myeloma Information Specialists (MIS) to understand their diagnosis, disease, treatment options, and gain practical advice on living well with this blood cancer. Tailoring information and support to answer the questions and concerns of each service user, whilst taking account of the personal preferences and priorities of patients and their families, ensures the MIS team deliver the gold standard of care of personalised support. By preparing patients and families for future consultations with their healthcare team and guiding them through their cancer journey, the MIS team can assist each service user to self-manage their cancer and personal circumstances.

Key Points

- The availability to tailored information and support during COVID-19 is essential to patients with myeloma and related conditions as they are at increased risk of infection and complications of COVID-19.
- The Myeloma UK Myeloma Infoline helpline and Ask The Nurse email services saw an unprecedented increase in service demand as a result of COVID-19.
- The helpline and email services adopted new ways of working and introduced other key knowledgeable members of staff to assist with increased demand.
- Patients with myeloma and related conditions and their families required tailored information and support during COVID-19 to understand the shielding, stay at home and self-isolating UK Government guidance.
- By clarifying the content of the guidelines and demonstrating how this information would apply to their day-to-day activities, service users could self-manage their situation and felt empowered.
During the initial phase of the pandemic in March 2020, where the Government put in place the lockdown measures and asked the public to follow the guidelines, our team needed to interpret the generic details provided by the Government and make them accessible and relevant to anyone affected by myeloma and related conditions. The MIS team responded quickly to the COVID-19 crisis and worked closely with colleagues across Myeloma UK to effectively and knowledgeably respond to the complex queries of service users.

Our services experienced an unprecedented increase in demand during the pandemic. Figure 1 shows the number of service users contacting the team in March 2020 compared to March 2019. The demand for our services demonstrates the valuable resources we provide for service users and the high standards of care the team deliver. Responding effectively to this increase required modification of our service provision both in terms of speed of delivery and the fact that we moved to home working. To offer a sustainable service, highly knowledgeable staff members from across the organization assisted in delivering the Myeloma Infoline and ATN services; the team grew from 4 to 9 staff. This provided some relief to the existing team and ensured the service could be delivered at scale.

Tailoring the guidelines to the specific nuances and complexities of myeloma and their related conditions has been far from straightforward. Considerable efforts have been made to decompose the various guidelines and how they affect patients and families so that tailoring to individual needs could be achieved. Inevitably, this approach takes time to prepare, requires careful consideration of the wider context of care, the individual preferences and priorities of service users, the risks associated with COVID-19 and how to minimise that risk in an environment where there are many uncertainties and unknowns. By engaging service users in an honest discourse regarding the complications of COVID-19, we prepared service users to make decisions to reduce their risks and self-manage their individual circumstances during lockdown.

In the early phase of the pandemic, where the population was asked to engage in health behaviour change and use more rigorous hygiene practices, this was not a major step-change for our service users. Most myeloma patients and their families, as well as those with related conditions, are fully aware of the need to undertake rigorous hygiene practices because they know they are at increased risk of infection compared to the general population. However, service users found it difficult to interpret the public health messaging provided by the guidelines and more specifically the stay-at-home, shielding and self-isolating guidance (see Appendix S1). In many cases, patients and families found it difficult to digest the information and each term was often used interchangeably by service users. By clarifying the content of the guidelines and subsequently demonstrating how this would apply to their day-to-day activities (ie, going out to work, seeing their families, attending clinical appointments, and receiving treatments) service users could self-manage their situation and felt empowered (see Appendix S2, for an example).

2 | CONCLUSIONS

Whilst changes to lockdown will inevitably bring new challenges as we all adjust to a "new norm", our services will continue to respond effectively and compassionately to service users. As a team, we share responsibility to develop and provide tailored information and support that empowers patients and families to take sensible steps to reduce their risks of infection. Taking this approach means we can
ensure patients and families psychological and emotional wellbeing is maintained and supported throughout COVID-19 and beyond.

CONFLICT OF INTEREST
The authors declare that they have no conflicts of interest.

DATA AVAILABILITY
The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION
Additional supporting information may be found online in the Supporting Information section at the end of this article.

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