

Peer-to-Peer Support

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Introduction

I am Jon Mathias, Co-Chair of MPN Voice, a patient support and advocacy group in the UK, and a founder and steering committee member of MPN Advocates Network.

Disclosures

Over the past five years, I have received honoraria from Novartis and GSK

MPN Voice and MPNAN receive grants from a wide range of industry sponsors to support our work

I also have a vested interest in MPN research and clinical practice, having been diagnosed with ET in 1998.



The Origin of our 'Buddy' System

MPN Voice started with small meetings of patients at St Thomas' Hospital in London, with presentations from MPN specialists and patients.

Very soon, we realised that patients valued the face-to-face contact with other patients as much as the medical information

At first we started arranging patient-to-patient contact on an as-needed basis – very informally and not publicized

The rapid popularity of individual contact meant that we needed to organize a more formal system



Benefits

All patients have different needs and therefore get different benefits from individual contact.

We believe the principal benefit, even if people sometimes don't describe it directly, is a sense of empathy and emotional connection; a feeling of not being alone

Patients, especially those with a new diagnosis, also value practical advice, information and 'signposting' from more experienced patients

Employment and insurance issues
Travel advice
Health system navigation
Benefit claims

Limitations

We have to be very clear with our buddies that we cannot give medical advice

We are also not lawyers and all buddies need to be careful that the conversations should not be interpreted as legal advice

We do not tell or instruct patients what to do and we are not a service that is accountable in the same sense as a government agency

How it works

Our system in MPN Voice has been running for several years and has gradually evolved into a sustainable and efficient process.

When a patient offers their time to be a buddy, we arrange a phone/zoom call to judge their suitability and then provide an information booklet. Nearly all patients offering to be buddies have been 'buddied' themselves.

We have a Buddy Coordinator who maintains a database of all our members who are currently available to be buddies. This records their contact details, location, gender, diagnosis and buddying history.

When a patient reaches out to request a buddy (normally by email), after a conversation with the coordinator about their situation and needs, the coordinator will match the patient with an appropriate buddy and then that buddy will be asked if they are willing and able to be the buddy for the patient

Practicalities

We monitor buddy activity informally but recognise that, once contact has been made, it is up to the buddy-buddy pair to decide on how often to talk, etc.

The database of buddies contains sensitive personal information and is governed by data protection regulation (e.g. GDPR)

A coordinator (or a team) needs to be available to respond to contact from either buddy at all times

We organise occasional meetings of buddies to discuss and share best practice, concerns, successes

Thank you for listening

Questions ?

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