

MPNs impact the patient and everyone around them

The lives of partners, children, parents and everyone in the patient's circle are affected by the disease

Emotional and Psychological Impact – patients' loved ones share the fear and anxiety that the patient feels

Economic Impact – carers often have to reduce or stop working altogether

Children - How and whether to explain the disease?

Practical Concerns - employment, insurance, finance, travel
Navigating health systems

Families and Patients benefit from support

Feedback tells us that family members appreciate being included in the conversation

Their **fears and anxieties** are recognised and discussed

Families are able to share their stories and offer **empathy and practical advice**

Family members tell us that they can **support the patient more** because of better understanding

MPN Voice recognises the impact on families

We encourage patients to include their families and friends to be involved in their journey. MPN Voice treats family members as a special sub-group of our membership

We arrange specific **Family Break-Out Groups** at our face-to-face and online meetings

Break-Outs are **facilitated** by clinicians and patient advocates

Family members and friends are included in our **Buddy Programme** – families can be put in touch with others in the same situation

Family members use the MPN Voice online forum on **HealthUnlocked** to discuss concerns

What we have learned

We need to think about families' concerns as **separate but related to the patients' own**

Families might need **encouragement** to be involved

Support for families and friends needs to be **resourced properly** – space and time at meetings; facilitation; buddies willing and able to work with others