

How to run an effective and supportive helpline for patients/families

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Sarcoma UK



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Sarcoma UK is a national charity that funds vital research, offers support to anyone affected by sarcoma cancer and campaigns for better treatments. It is the only cancer charity in the UK focusing on all types of sarcoma



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Background



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How did it all begin?

- In 2014-15 the office team were receiving more and more complex calls into the office
- Questions that they were not able to answer
- Upset callers who needed advice and support
- Calls that could be too complex or difficult for staff to answer



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What would it look like?

- A support line for anyone with questions about sarcoma
- Answered by Claire (Head of information and support) and a trained health professional
- Free telephone number and email address



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Why a trained health professional?

- The charity wanted to be able to answer questions to a very high level
- We needed someone with the sarcoma experience, not just a nursing background
- Sarcoma is very complex, not everyone with the 'same' diagnosis will have the same treatment or outcome
- We needed someone that callers could trust was giving them the correct information
- It was hoped that having someone who already knew the specialist clinical teams would help with the promotion of the service



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Who would this person be?

- Needed to have senior clinical sarcoma experience
- Needed to be able to work autonomously
- Needed to be a good communicator
- Needed to be able to set up the service and adapt it as, and when, it was needed



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Go Live!

- On February 8th 2016 the support line was opened
- 20 hours per week
- Via a call handling system
- Freephone number and email address
- In the first month the team had 52 contacts from 36 individuals



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Sarcoma UK Support Line



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Sarcoma UK support line



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Sarcoma UK Support Line

Telephone - 0808 801 0401

Email - supportline@sarcoma.org.uk

Text - 07860 058830



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The Support line team

Helen – Sarcoma Specialist Nurse – over 20 years experience, many of which were as an advanced nurse practitioner with the Oxford Bone and Soft tissue team

Sam – Sarcoma Specialist Nurse – Over 20 years experience, many of which as a Clinical nurse specialist with the Royal Marsden Soft tissue team

Joshna – Sarcoma specialist OT – over 20 years experience, 10 of which were with the Stanmore Bone and Soft tissue team



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What is the Support Line?

- Phone, Text or e-mail contact
- For anyone affected by sarcoma
- Expert Support
- Open 25 hours a week
- Mon – Fri 10am – 3pm



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What is the support line not?

- It is not a second opinion line
- It is not a way of getting quicker referrals
- It is not a way of accessing clinical teams
- It is not a complaints line



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Aim of the Support Line

- To be independent and confidential
- To offer TIME and a listening ear
- Point people in the right direction



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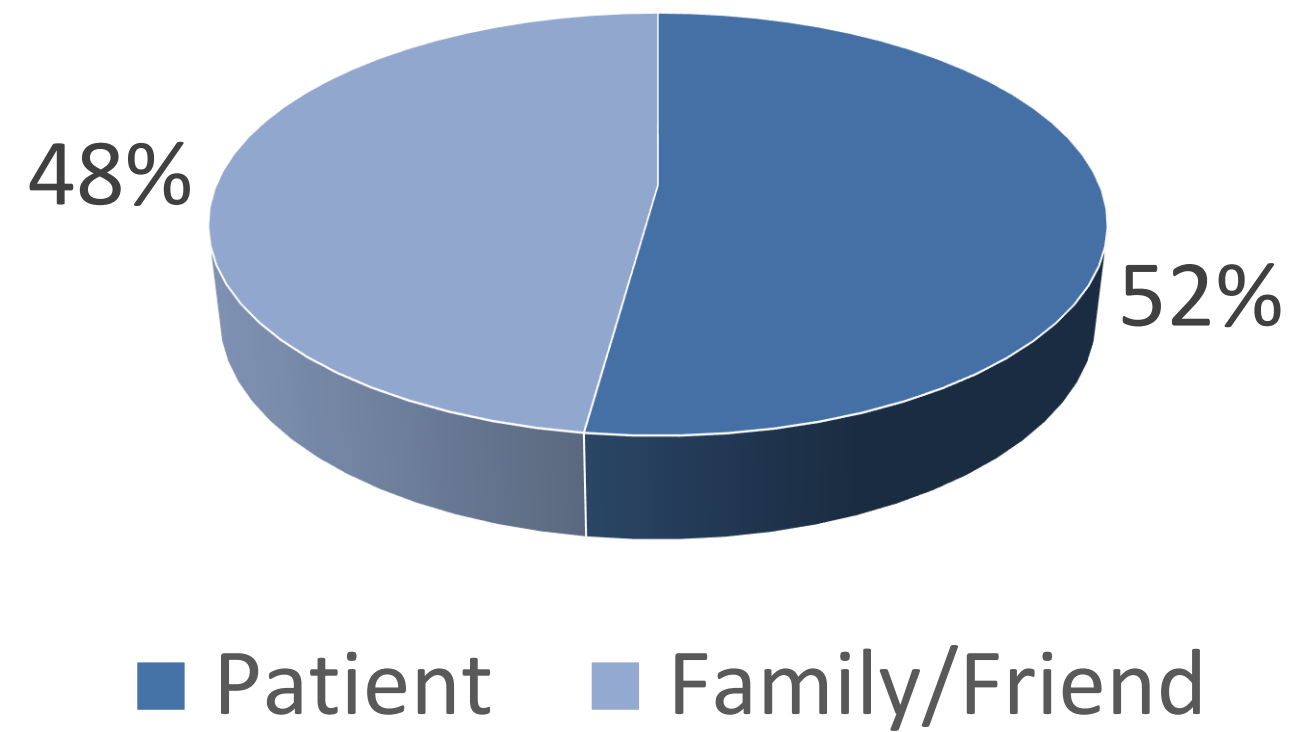
Facts and figures

- Over 6200 contacts from more than 1750 individuals
- More than 80 patients moved to the appropriate MDT
- Contact made from every continent except the snowy one
- Preferred contact seems to be email



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Who contacts us?



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What do the patients ask?

- Dr 'Google' - anxiety
- Suspected or newly diagnosed
- Rubber stamping
- Cross roads in the cancer pathway
- End of treatment options



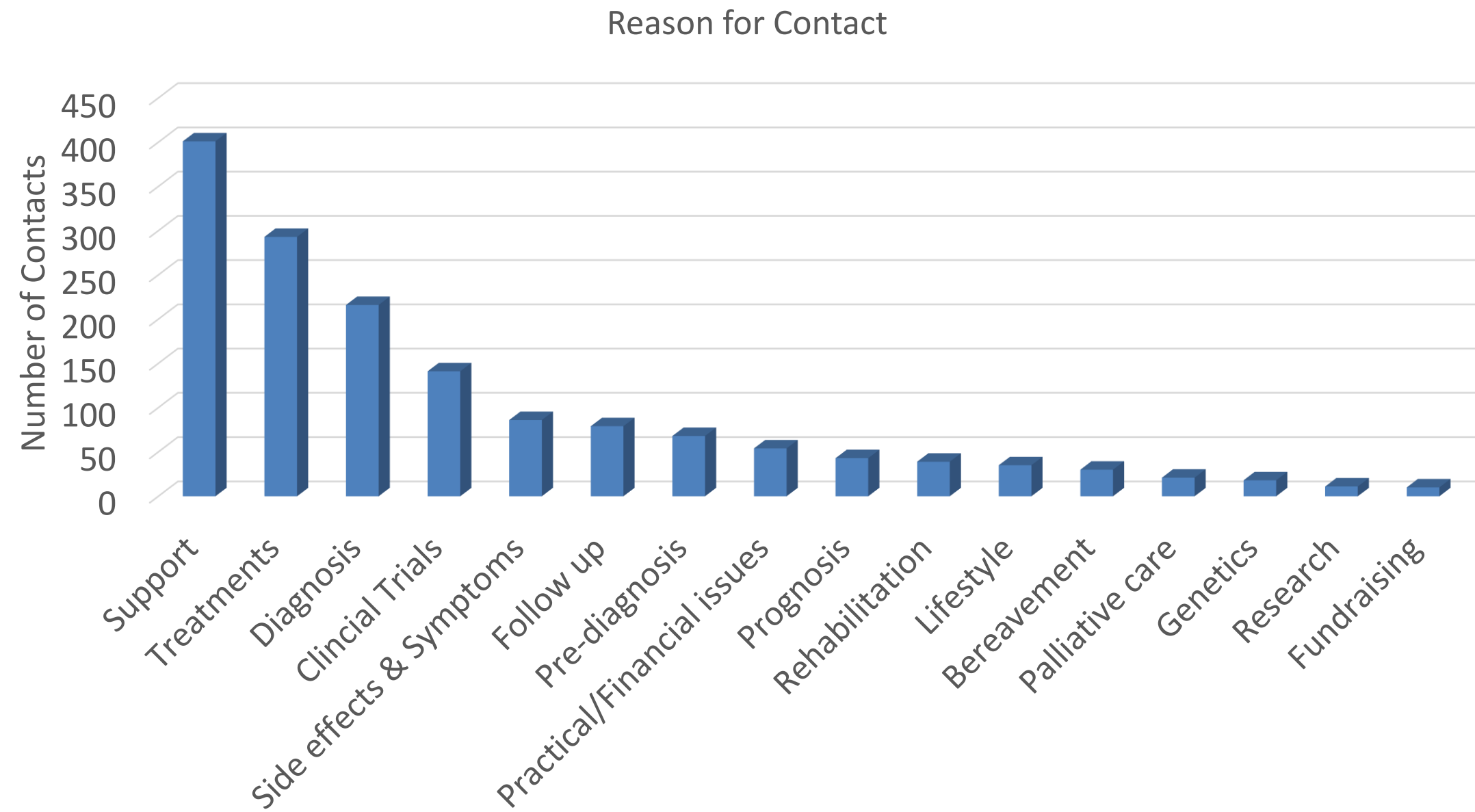
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What about family and friends?

- How can they help, what should they say
- Searching for options- phase 1
- Making sense of the situation and what it means for the future
- Bereavement



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Reason for Contact



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Health professionals

- Junior doctors/ GP/ Medical advisors
- Where and how to refer
- Requesting specific information and support groups



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Audit

- Audit is important to be able to show the impact of a service and look for future improvements
- The SL is audited every 6 months, and 3 months after any change to the service
- The last audit April-Sept 2019 showed an increase of contacts of 58.7% on the same period the previous year



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Audit

- Since changing our opening hours we have seen a reduction in the people trying to contact the SL team out of hours by 51.2%
- However, the number of people connecting to voicemail when the line is open has increased by 33.6%
- On average a call lasts for 26.18 mins and the team spent 123.9 hours on the telephone in this 6 months period, and increase of 24.1% on the same period of the previous year
- The number of telephone contacts also increased by 40.9%



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Cost

• Helplines partnership membership and admin fee	828
• Call handling virtual call centre	1380
• Call handling quarterly usage charges	1760
• Call handling text chat	1200
• Call and text charges vonage based on average 19/20	600
• Support line marketing	250
• Total	£6,018



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Feedback

- “Thank you so much for your response. It’s both detailed and super clear. I really appreciate the time, effort and expertise in responding to my question and it has made me more confident and less anxious. Thank you so much”
- “I was very much reassured by the answer I received to my question. I really like being able to communicate via email as that suits me best. Thanks for being there, you do wonderful work!”



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What have we learnt?

- Working on the support line is VERY different to working in clinical practice
- You have to LISTEN
- You have to believe that everyone is telling you the truth
- Not everyone will want information in the same way
- Contacts can be very simple or very complex
- Not knowing the answer is OK, but knowing where to get it from is imperative



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Top Tips for anyone wanting to start a helpline

Be clear about the service you provide:

- Opening times
- Access – Telephone, email, other
- Who is offering the service – HCP's, Patients, Volunteers
- What the service offers – support, advice, clinical information
- Aim to have back up for tricky questions



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Top Tips

- Answering a help line is not always easy
- If using patients/volunteers make sure you have support in place for them (clinical supervision)
- Try to ensure contact is made to a dedicated number/email address so people aren't using their own mobile/house phone numbers
- Promotion is key to a successful service



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Conclusion

An expert support line is expensive

It is highly regarded by health care professionals

Well evaluated by users

Provides an 'extra' to the support already offered

The team feel very privileged to undertake this work to help all those affected by sarcoma



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The background is a solid teal color with several concentric, semi-transparent circular bands of a slightly lighter shade of teal. These bands are centered around the text and create a subtle, layered effect.

Thank you