

# SPAEN

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**Sarcoma**<sup>UK</sup>  
Support Line  
0808 801 0401

[supportline@sarcoma.org.uk](mailto:supportline@sarcoma.org.uk)



The bone & soft tissue cancer charity

# MDT and Support Line

- Role of the nurse in the sarcoma multi-disciplinary team (MDT)
- Sarcoma UK Support Line



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# Nurses in the MDT

- UK NICE guidelines include the role of a point of contact which is usually a nurse
- Clinical expertise to patients, families and other professionals
- Support the patient/family throughout the sarcoma pathway
- Key role in coordinating the pathway
- Act as the patient advocate

# Patient Outcomes

- Alleviation of suffering – physical assessment and specialist symptom management
- Assessing and meeting information needs of patients
- Rescue work
- Alleviation of suffering – psychological
- Access to a key contact/knowledgeable professional, or brokering rapid access to another professional



# Sarcoma UK support line



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# What is the Support Line?

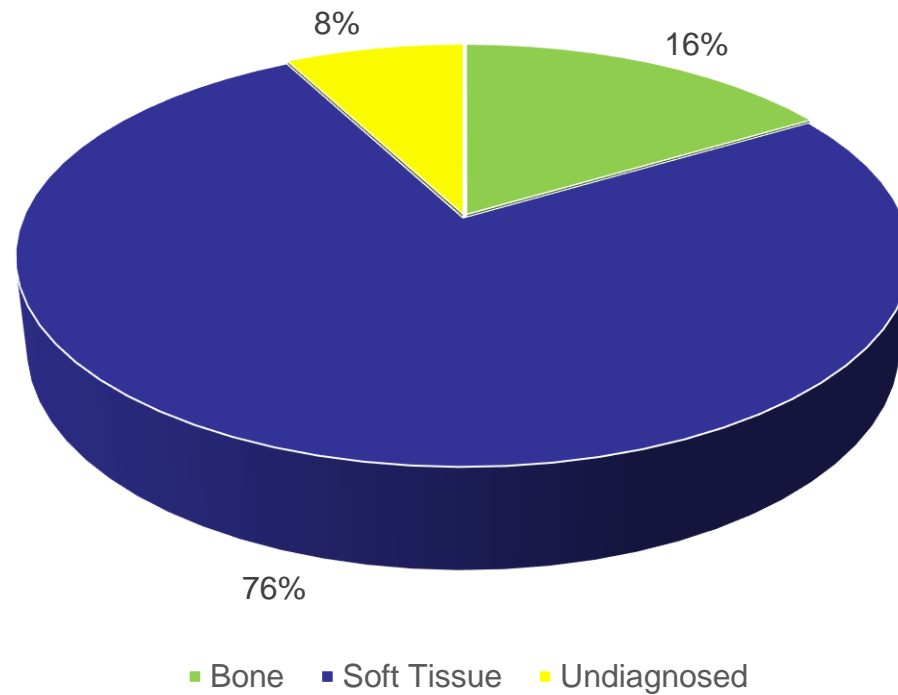
- Phone or e-mail contact
- Sarcoma UK is here for every person affected by sarcoma
- Open 20 hours a week
- Expert Support

# Aim of Support Line

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

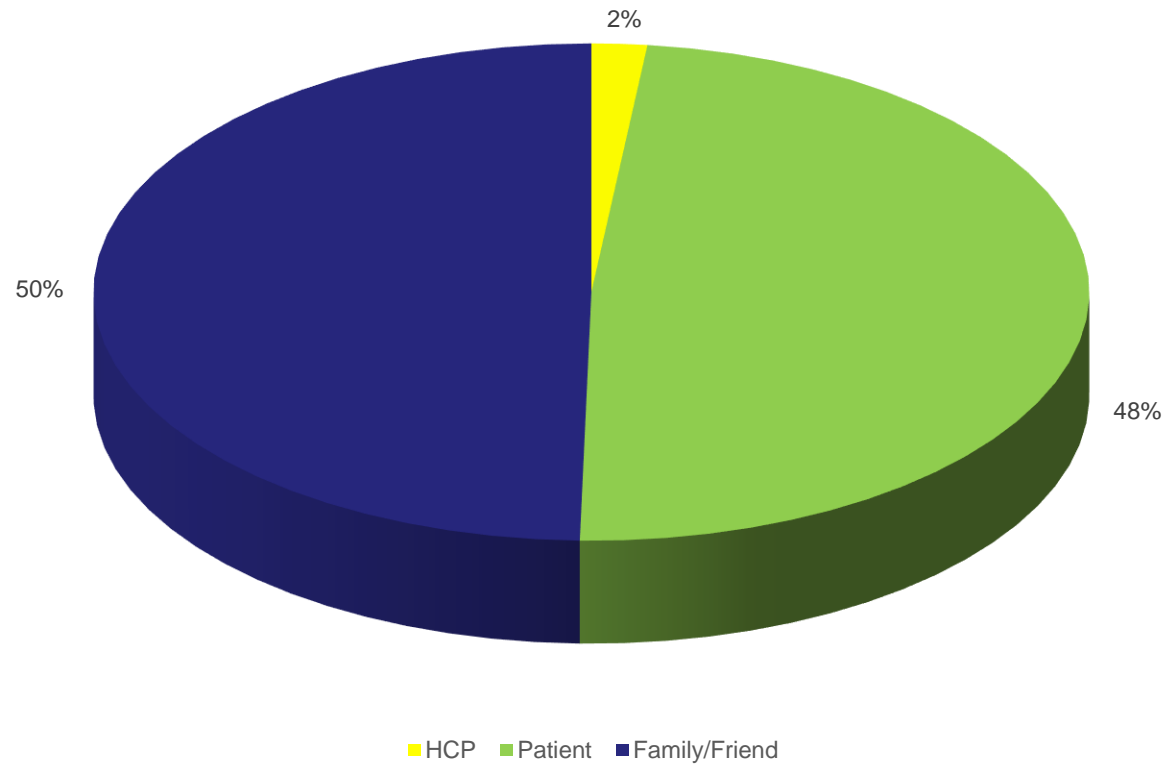
# Sarcoma types

Sarcoma types:





Contacts from:



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# What do the patients ask

- Dr 'Google'- anxiety
- Suspected/newly diagnosed
- Trials
- Cross roads in the cancer pathway
- End of treatment options

# What about family and friends

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

# Health professionals

- Junior doctors/ GP/ Medical advisors
- Where and how to refer
- Requesting specific information
- Information on support groups
- Direct referrals from consultants

# Support Line Audit Data

- 2477 contacts
- Ring 3 times
- 13 patients directed to sarcoma service
- 1788 emails
- 689 telephone conversations
- 27minutes

- We have taken calls/emails from every specialist centre, in every region of the UK, and every continent apart from Antarctica
- People from 34 countries have contacted us

# What difference does it make?

- Man in his 30's, very anxious
- Long term follow up issues
- Sent an email documenting what we discussed for clarity
- Help pose some question for clinic
- Next clinic more productive

*“It was so lovely to speak to you the other day.... it's feels good to get everything off my chest and be listened too. Makes the difference to know there is a service where all ones concerns can be raised and talked about.*

*The email you sent is fantastic, and gives me some constructive advice and ideas of other questions I can put forward to get some answers, actions and reassurance.”*





- Wife rang to say husband had been in hospital for 6 weeks
- Large fatty tumour around his kidneys
- Suggestion it was a sarcoma, planning to operate locally
- Helped them get a referral into sarcoma unit, had appropriate surgery

*‘The support and advice you gave us in just a few days made a huge difference, we got to the right team and he had his surgery the same week, 6 weeks later he was back at work!’*

# What have we learnt?

- Building relationships without meeting
- Giving callers the tools to have a voice
- Clinical trials- difficult to access useful information
- Support line is needed and is being used
- Scan- Anxiety !

# Feedback into our work

- Clinical trials hub
- Lymphoedema
- Information around the diagnosis process
- Feedback into regional, national and international meetings
- Desmoid –support group

Thank-you