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# Bone & Soft Tissue Tumours

A guide for patients referred about a bone or soft tissue tumour

This booklet is general information to read at your own pace. It is not medical advice and does not replace a consultation. Treatment differs from person to person — please discuss what is planned for you with your treating team. Appointments: (02) 9052 1883.

# Bone & soft tissue tumours

A guide for patients referred to the RPA Bone & Soft Tissue Sarcoma Unit — what sarcoma is, the tests, how treatment is planned by the specialist team, and what to expect from surgery, hospital and follow-up.

If you are reading this, you or someone you care about has probably been told they have — or might have — a bone or soft tissue tumour. That is frightening to hear, and the first thing worth knowing is that **most lumps are not cancer**, and that even for those that are, there is a clear, well-practised path through diagnosis and treatment.

This guide is based on the patient booklet given to people having orthopaedic tumour surgery at Royal Prince Alfred Hospital (RPA). Your family members or carers may also find it helpful to read. It explains the tests, the team, the types of surgery, and the practical details of a hospital stay — including help with travel and accommodation if you live outside Sydney.

Two things to hold onto as you read:

**You will be looked after by a team, not a single doctor.** RPA is a specialist sarcoma centre. Every patient's case is discussed at a multidisciplinary team (MDT) meeting, where sarcoma surgeons, oncologists, radiologists and pathologists agree on the best plan together. The evidence is clear that people with sarcoma do better when treated this way.

**This information is general.** Sarcomas differ enormously in type, size and position, and treatment is planned for each person individually. Use these pages to prepare your questions — then ask your treating team what is planned for *you*. You will be given extra information by hospital staff about your individual needs.

If you have questions or concerns at any point, speak to your treating team. Patients of the RPA sarcoma service and their families can also call the **RPA Virtual Hospital's Sarcoma & Tumour Advice and Support Service on 1800 463 918, 24 hours a day, 7 days a week** (not for emergencies — in an emergency call 000).

**SOURCES**

1 Cancer Australia — Sarcoma — https://www.canceraustralia.gov.au/cancer-types/sarcoma

2 Cancer Council Australia — Sarcoma, Guide to best cancer care — https://www.cancer.org.au/cancercareguides/sarcoma

3 Australia and New Zealand Sarcoma Association (ANZSA) — Australian Sarcoma Management Guidelines — https://sarcoma.org.au/pages/sarcoma-guidelines

4 RPA Bone and Soft Tissue Tumour & Sarcoma Patient Booklet, Royal Prince Alfred Hospital

# What is sarcoma?

What sarcoma is, how bone sarcoma differs from soft tissue sarcoma, and the common types — in plain terms for patients newly referred.

Sarcomas are an uncommon group of cancers that arise in the body's supporting, or connective, tissues — the framework of bone, cartilage, muscle and fat that holds the body together and lets it move. Because that framework runs everywhere, a sarcoma can appear almost anywhere. It begins when cells in one of these tissues start to divide and multiply without the usual controls.

Rarity shapes the whole experience of sarcoma. Soft tissue sarcomas account for only a small fraction of all cancers in Australia — of the order of a couple of thousand new cases across the country each year — so a typical GP may encounter only a handful across an entire career, and the great majority of lumps they assess prove to be harmless. That rarity is precisely why anything suspicious is sent to a specialist unit, where the same tumours are seen every week and the team knows what to look for.

Sarcomas fall into two broad families, grouped by the tissue in which they begin.

## Soft tissue sarcoma

Soft tissue sarcomas develop in the soft, supporting tissues of the body: fat, muscle, blood vessels, lymphatic vessels, nerves, tendons and cartilage. There are more than 50 types. The most common include:

- **Undifferentiated pleomorphic sarcoma (UPS)** — most common in people aged 50 to 70
- **Leiomyosarcoma** — starts in smooth muscle, often in the limbs, abdomen or uterus
- **Liposarcoma** — starts in fat cells, often in the trunk, limbs or abdomen
- **Angiosarcoma** — starts in blood vessels or lymphatic vessels
- **Malignant peripheral nerve sheath tumour** — starts in the lining of nerves, often deep in the arms, legs or trunk
- **Fibroblastic sarcoma** — develops in the fibrous tissues, often in the limbs, skin or trunk
- **Rhabdomyosarcoma** — develops in skeletal muscle, most common in children under 10
- **Synovial sarcoma** — develops in cells around joints and tendons

## Bone sarcoma

Primary bone sarcoma starts *in* the bone itself. This is different from **bone metastases** — cancer that has spread to the bone from somewhere else, such as the breast or lung. The two are treated quite differently, which is one reason accurate diagnosis matters so much.

Bone sarcomas are more common in children and teenagers than in adults. The main types are:

- **Osteosarcoma** — the most common primary bone cancer. It usually occurs at the ends of the long bones, especially around the knee
- **Ewing sarcoma** — common sites include the pelvis, the chest wall and the middle of the long bones in the legs; it can also form in soft tissue
- **Chondrosarcoma** — starts in the cells that make cartilage, and often affects the upper arm, legs, pelvis, ribs or shoulder blade

## What does this mean for you?

The name of your tumour — its exact type and grade — determines everything that follows: which tests you need, whether surgery comes first or after other treatment, and what follow-up looks like. Working that name out precisely is the purpose of the tests described in the next step.

**SOURCES**

1 Cancer Australia — Sarcoma — https://www.canceraustralia.gov.au/cancer-types/sarcoma

2 Cancer Council Australia — Soft tissue sarcoma — https://www.cancer.org.au/types-of-cancer/rare-cancers/soft-tissue-sarcoma

3 Australia and New Zealand Sarcoma Association (ANZSA) — https://sarcoma.org.au/

4 RPA Bone and Soft Tissue Tumour & Sarcoma Patient Booklet, Royal Prince Alfred Hospital

# Tests and diagnosis

The scans and tests used to diagnose and stage a bone or soft tissue tumour — X-ray, MRI, CT, PET and biopsy — and why the biopsy should only be done at a specialist sarcoma centre.

Before any treatment can be planned, the team needs to know exactly what the tumour is, exactly where it is, and whether it has spread. That takes a series of tests, usually over a few weeks. Waiting for results is often the hardest part of the whole journey — it helps to know what each test is for.

## The tests you may have

**Clinical examination.** The specialist will look at and feel the lump or the affected area, and ask about your history — how long it has been there, whether it is growing, whether it hurts.

**X-ray.** A quick, simple picture, most useful for tumours in bone.

**MRI scan.** Magnetic resonance imaging uses a strong magnet and radio waves — no X-rays — to map the tumour and everything around it, including muscle, nerve and blood vessels. It is the scan surgeons rely on most when planning an operation. It does not hurt, but it means lying still inside a tunnel for a while, so let the staff know beforehand if confined spaces trouble you.

**CT scan.** A CT combines X-rays with computer processing to produce thin cross-sectional slices through the body. A scan of the chest is usually included, because if a sarcoma is going to spread, the lungs are where it most often shows up first.

**PET scan.** A PET scan measures activity rather than shape. A trace of a short-lived radioactive sugar is injected, and because many tumours consume sugar faster than surrounding tissue, active areas light up on the images in a way an ordinary scan would not show.

**Biopsy.** Using a needle and local anaesthetic, a small sample of the lump is taken for the laboratory, with a CT scanner or ultrasound steering the needle to precisely the right spot.

## Why the biopsy matters so much

The biopsy is the test that gives the tumour its name. An expert pathologist examines the cells under the microscope, often with special testing. This usually takes several days, sometimes longer — a frustrating wait, but a precise answer matters more than a fast

one.

Sampling a suspected sarcoma is not a routine biopsy. **It should be carried out only at a specialist unit, by an interventional radiologist who performs these regularly** — because the exact path the needle takes has to be chosen so it can later be removed with the tumour. A sample taken along the wrong track can jeopardise the definitive operation, which is why the biopsy is planned by the very team that will operate. Being referred to RPA *before* a biopsy is therefore a good sign, not a hold-up.

## Staging — putting the results together

Together, these tests tell the team where the tumour is, whether it is growing, and whether it has spread. This is called **staging**. The stage, along with the tumour's type and grade from the biopsy, is what the multidisciplinary team uses to work out the best treatment plan for you — which is the subject of the next step.

You can bring a family member or friend with you to any of your appointments. Four ears are better than two, and there is a lot to take in.

**SOURCES**

1 Cancer Council Australia — Sarcoma, Guide to best cancer care (specialist biopsy; timeframes for diagnosis) — https://www.cancer.org.au/cancercareguides/sarcoma

2 Cancer Council Australia — Soft tissue sarcoma — https://www.cancer.org.au/types-of-cancer/rare-cancers/soft-tissue-sarcoma

3 RPA Bone and Soft Tissue Tumour & Sarcoma Patient Booklet, Royal Prince Alfred Hospital

# How treatment is planned

Why sarcoma should be treated at a specialist centre, what the multidisciplinary team (MDT) meeting is, and the evidence that outcomes are better when care is planned this way.

## Why a specialist sarcoma centre

Sarcoma is rare, and rare conditions are handled best where they are common. For that reason, Australian and international guidelines advise that anyone with a confirmed or suspected sarcoma be sent to a dedicated sarcoma unit rather than managed locally.

This is more than a matter of paperwork. Studies comparing specialist units with general hospitals point consistently in the same direction — people tend to do better when a sarcoma is operated on at a centre that treats it regularly:

- the tumour is more often fully cleared at its original site
- recovery from the operation tends to go more smoothly
- survival is longer on average
- when radiotherapy is planned and given at a specialist unit, the cancer is less likely to come back locally and side effects tend to be fewer

Royal Prince Alfred Hospital is one of those centres. Its Bone & Soft Tissue Sarcoma Unit treats bone and soft tissue tumours — malignant and benign — with surgery performed at RPA and the Institute of Rheumatology and Orthopaedics (IRO) on the same campus.

## The multidisciplinary team (MDT)

No single doctor, however experienced, should plan sarcoma treatment alone. At RPA, every patient's case is discussed at a regular **multidisciplinary team meeting** — usually called the MDT.

Around the table are the people whose combined judgement your plan needs:

- **Orthopaedic and plastic surgeons** — the operation and the reconstruction
- **Medical oncologists** — chemotherapy and drug treatment
- **Radiation oncologists** — radiotherapy
- **Radiologists** — reading your scans
- **Pathologists** — the exact diagnosis from your biopsy

- **Clinical nurse consultants (CNCs)** — coordinating your care and keeping you informed

The MDT looks at your scans, your biopsy results and your staging together, and agrees on a recommended plan: whether surgery should come first, whether chemotherapy or radiotherapy should come before or after it, and what kind of operation gives the best result.

## What this means for you in practice

Your treatment plan may involve more than one kind of treatment, in a deliberate order. For some tumours, surgery comes first. For others, chemotherapy or radiotherapy is used *before* surgery to shrink the tumour and make the operation safer and more effective. The next two steps explain the surgery itself and these other treatments.

Your first consultation with the surgical team usually happens once the preliminary tests are done and there is enough information to begin forming a plan. Bring someone with you if you can, and bring your questions written down — no question about your own treatment is too small to ask.

Your **clinical nurse consultant** is your continuing point of contact throughout: if you are unsure who to ask about anything, start with them.

**SOURCES**

1 Australia and New Zealand Sarcoma Association (ANZSA) — Australian Sarcoma Management Guidelines, Topic 1 (treatment at a specialised sarcoma centre) — https://sarcoma.org.au/pages/sarcoma-guidelines/topic-1-treatment-at-specialised-sarcoma-centre

2 ESMO–EURACAN–GENTURIS–ERN PaedCan Clinical Practice Guidelines — Bone sarcomas (Annals of Oncology, 2021) — https://www.annalsofoncology.org/article/S0923-7534(21)04280-0/fulltext

3 Cancer Council Australia — Sarcoma, Guide to best cancer care — https://www.cancer.org.au/cancercareguides/sarcoma

4 RPA Bone and Soft Tissue Tumour & Sarcoma Patient Booklet, Royal Prince Alfred Hospital

# Surgery for sarcoma

The types of operation used for bone and soft tissue tumours — wide resection, bone and joint replacement, skin grafts, and amputation — explained plainly and honestly.

Orthopaedic tumour surgery is performed at Royal Prince Alfred Hospital and the Institute of Rheumatology and Orthopaedics (IRO) for a wide range of malignant and benign tumours.

For many sarcomas, an operation is the main treatment and often the first step. The goal can be put simply: **take out the whole tumour, and with it a surrounding cuff of healthy tissue.** Surgeons call that cuff a *margin*. Leaving a margin catches the stray cancer cells that are too small to see at operation, and lowers the chance of the tumour regrowing where it started.

Exactly how this is done depends heavily on where the tumour is and how big it is. The main types of operation are set out below — but please read the note at the end of the page before assuming any of them applies to you.

## Wide resection

This is the standard sarcoma operation. The tumour is taken out in one piece together with the healthy tissue immediately around it, so that the edge of what is removed is clear of cancer on every side. For many soft tissue sarcomas, a wide resection is the entire surgical treatment.

## Bone or joint replacement (endoprosthetic reconstruction)

When a tumour involves bone, removing it with a proper margin can mean taking a significant length of bone — sometimes including a joint. In that case the missing bone is rebuilt with an implant (an *endoprosthesis*), allowing you to keep the limb. These reconstructions are generally more extensive than a standard hip or knee replacement, and they are one of the reasons this surgery is done at a specialist centre.

## Skin grafts and flaps

If removing the whole tumour leaves a wound too large to close with stitches, a plastic surgeon — part of the same team, often in the same operation — closes it with a skin graft: a thin layer of skin taken from a healthy area and carefully placed over the surgical site. Larger defects are sometimes closed with a *flap*, tissue moved with its own blood supply.

## Amputation

Sometimes part or all of a limb must be removed to treat the cancer — when the tumour is too large, or involves critical structures such as major nerves and blood vessels, and cannot be removed any other way. This is much less common than it once was, but for some tumours it remains the operation that gives the best chance of cure.

If amputation is being considered in your case, it will be discussed with you fully and honestly, with time for your questions, and with support around you — including rehabilitation specialists, prosthetic services and psychological support. You will not be walked into that decision.

## One important note

Because the operation depends so much on the individual tumour, **everything above is general information and may not match your situation.** Ask your surgeon what is actually planned for you, and keep asking until you could describe your own operation in your own words. Far from being a nuisance, that is exactly what the team hopes you will do.

**SOURCES**

1 ESMO–EURACAN–GENTURIS Clinical Practice Guidelines — Soft tissue and visceral sarcomas (Annals of Oncology, 2021); wide excision as the mainstay of local treatment — https://www.esmo.org/guidelines/guidelines-by-topic/sarcoma-and-gist/soft-tissue-and-visceral-sarcomas

2 Cancer Council Australia — Soft tissue sarcoma — https://www.cancer.org.au/types-of-cancer/rare-cancers/soft-tissue-sarcoma

3 RPA Bone and Soft Tissue Tumour & Sarcoma Patient Booklet, Royal Prince Alfred Hospital

# Chemotherapy and radiotherapy

When drug treatment or radiotherapy is used for sarcoma — before or after surgery — and what being referred to Chris O'Brien Lifehouse means.

Surgery removes a sarcoma from where it is. For some sarcomas, the best plan also includes *systemic* treatment — treatment that works through the whole body — or radiotherapy focused on the tumour site. The MDT may recommend these **before** surgery, **after** it, or occasionally instead of it.

If this is part of your plan, you will be referred to the appropriate team at **Chris O'Brien Lifehouse** — the comprehensive cancer centre directly beside RPA on Missenden Road — or, where possible, to a cancer service closer to your home.

## Chemotherapy

Chemotherapy uses anti-cancer drugs to destroy cancer cells. It is given intravenously (through a drip) and sometimes by mouth, usually in cycles with recovery time between them. For sarcoma it is **most often used for bone sarcomas**, such as osteosarcoma and Ewing sarcoma.

The timing has its own vocabulary, which you will hear at appointments:

- **Neoadjuvant** chemotherapy is given *before* surgery, to shrink the tumour and treat any microscopic spread early.
- **Adjuvant** chemotherapy is given *after* surgery, to reduce the chance of the cancer coming back.

If chemotherapy is recommended, you will be referred to a **medical oncologist** — a specialist in cancer drug treatment. They will explain which drugs, how many cycles, the likely side effects and how these are managed, and they will answer all of your questions about this kind of treatment.

## Radiotherapy

Radiation therapy (radiotherapy) uses precisely aimed high-energy radiation beams to destroy cancer cells in a specific area. For sarcoma it is **most often used for soft tissue sarcomas**, and — like chemotherapy — it can be given before or after surgery.

Planning matters enormously in radiotherapy: the aim is to treat the tumour bed thoroughly while sparing the healthy tissue around it. This is one of the areas where the evidence shows specialist-centre treatment gives fewer side effects and better control.

If radiotherapy is recommended, you will meet a **radiation oncologist**, who will explain the process in detail — the planning scans, the daily treatment visits, and what to expect during and afterwards.

## Living at a distance

Chemotherapy and radiotherapy involve repeated visits over weeks. If you live outside Sydney, tell the team early: treatment can sometimes be arranged closer to home, and where it cannot, the social work team can help with accommodation and with the **IPTAAS travel and accommodation subsidy** — both covered in the next step.

**SOURCES**

1 ESMO–EURACAN–GENTURIS–ERN PaedCan Clinical Practice Guidelines — Bone sarcomas (Annals of Oncology, 2021); chemotherapy before and after surgery for high-grade osteosarcoma — https://www.annalsofoncology.org/article/S0923-7534(21)04280-0/fulltext

2 ESMO–EURACAN–GENTURIS Clinical Practice Guidelines — Soft tissue and visceral sarcomas (Annals of Oncology, 2021); radiotherapy with surgery for intermediate/high-grade tumours — https://www.esmo.org/guidelines/guidelines-by-topic/sarcoma-and-gist/soft-tissue-and-visceral-sarcomas

3 Cancer Council Australia — Soft tissue sarcoma — https://www.cancer.org.au/types-of-cancer/rare-cancers/soft-tissue-sarcoma

4 RPA Bone and Soft Tissue Tumour & Sarcoma Patient Booklet, Royal Prince Alfred Hospital

# Your hospital stay

The practical details of surgery at RPA — the team you will meet, the pre-admission clinic, what to pack, parking, accommodation, travel assistance (IPTAAS), physiotherapy and the RPA Virtual Hospital.

## Before you come in — the pre-admission clinic

Most patients attend a pre-admission clinic appointment before surgery, at one of:

- **RPA** — Royal Prince Alfred Medical Centre, Level 2, corner of Carillon Avenue and Missenden Road, Newtown
- **IRO** — Institute of Rheumatology and Orthopaedics, Level 6, Queen Elizabeth II Building, 59 Missenden Road, Camperdown

The purpose is to make sure it is safe to proceed with surgery and anaesthetic, and to tell you what to expect on the day. You may meet the anaesthetist and clinic nurse, and have basic tests — an ECG (heart tracing), blood tests, and sometimes a chest X-ray. Allow one to two hours.

**Blood thinners:** if you take medicines such as aspirin, warfarin or apixaban, these need to be stopped before surgery — but only on your team's instructions. Wait to be told when.

## The team you will meet

A lot of people will introduce themselves. Broadly:

- **The medical team** — your consultant surgeons (orthopaedic and, for many operations, plastic), surgical fellows, registrars, resident medical officers and interns. Someone from the team will see you every day. Although the team is large, **the consultant surgeon ultimately makes the decisions about your care**. If you or your family want a proper sit-down conversation, ask — a time can be arranged.
- **Nursing staff** — registered nurses provide your daily care around the clock; the Nursing Unit Manager runs the ward; and your **Clinical Nurse Consultant (CNC)** coordinates your care before and after surgery. The CNC is your key contact — their number is given to you directly.
- **Physiotherapist** — you will usually be seen on the day of your operation or the day after. Getting up and moving early is genuinely important: walking re-expands the lungs and helps prevent chest complications like pneumonia after an anaesthetic. You will start with a frame or other aid and progress from there; after discharge,

physiotherapy continues at a rehabilitation hospital or an outpatient clinic, whichever suits your needs.

- **Psychologist** — a sarcoma diagnosis is overwhelming, and a range of emotions is completely natural. The psycho-oncology service offers a safe space to work through stress, low mood, body-image changes and grief — in person or by video or phone, before or after surgery, and support may also be available for your loved ones.
- **Social worker** — practical and emotional support: financial assistance, transport, accommodation, carer support and community services. Ask any member of the team to connect you.
- Depending on your needs, you may also see an **occupational therapist, dietitian, pharmacist, Aboriginal liaison officer, speech therapist or interpreter**. RPA takes your cultural and religious needs into consideration wherever possible — let your nurse know what matters to you.

## What to bring

Comfortable and boring is the rule: toiletries and pyjamas, phone and charger, headphones, a book or magazines, an eye mask and ear plugs, photos if they help, and a small amount of money for a newspaper or café. Your valuables can be locked away during surgery, but you are responsible for what you bring — leave anything of value or sentimental importance at home.

The common wards for this surgery are **Q7E (elective orthopaedics, IRO)**, **8W1 (orthopaedics and trauma, RPA)** and **6E3 (plastic surgery, RPA)**; children are cared for on the children's ward, and some patients spend time in intensive care after larger operations — planned, not alarming. Guest Wi-Fi is available (network *SLHD-Guest*, sessions up to 12 hours).

## Parking, travel and accommodation

**Concession parking** is available for eligible patients and carers — including those attending for ongoing cancer treatment — and for holders of a Pension, Health Care, Gold Veterans or Mobility Parking card. Have the Concession Parking form signed by clinical staff and present it with your ID at the RPA Security Office, Level 5, Main Hospital Entrance (phone 9515 8409).

**If you live more than 100 km from Sydney**, you are entitled to claim a subsidy towards travel and accommodation through **IPTAAS — the Isolated Patients Travel and Accommodation Assistance Scheme** (iptaas.health.nsw.gov.au). The social work team and your CNC can help you apply, while you are an inpatient or at clinic

appointments.

**Accommodation** for you or your relatives can be arranged nearby — speak to your CNC, or call the RPA Accommodation Officer on 0407 672 351.

## Eating well

Cancer and its treatment place extra demands on the body. Eating well before, during and after treatment gives you more energy, helps wounds heal and tissues rebuild, supports your immune system, and can shorten hospital stays. During treatment you may need to be flexible — the foods you can manage may not match your normal diet, and that is fine. Check with your doctors before drinking alcohol during treatment, as it can interact with some medicines. The Cancer Council's *Nutrition for People Living with Cancer* booklet (linked below) is excellent, and the ward dietitian can help with specifics.

## The RPA Virtual Hospital — help, day or night

The **Virtual Sarcoma & Tumour Advice and Support Service** is a 24/7 clinical contact point for all patients of the RPA sarcoma unit or the Chris O'Brien Lifehouse sarcoma service — and for their carers and families.

Call **1800 463 918**, any time, about symptom management, pain, chemotherapy or radiotherapy concerns, or anything before or after your operation. If you need a healthcare interpreter, let them know.

**Not for emergencies — in an emergency call 000 or go to your nearest emergency department.**

**SOURCES**

1 RPA Bone and Soft Tissue Tumour & Sarcoma Patient Booklet, Royal Prince Alfred Hospital

2 IPTAAS — Isolated Patients Travel and Accommodation Assistance Scheme (NSW Health) — https://www.iptaas.health.nsw.gov.au/

3 Cancer Council — Nutrition for People Living with Cancer (2022) — https://www.cancer.org.au/assets/pdf/nutrition-and-cancer-booklet

# After treatment

Follow-up and surveillance scans, adjusting to changes in your body, what palliative care actually means, and the support services and contact numbers worth keeping.

## Follow-up — for years, on purpose

After surgery and treatment for sarcoma, you will have regular follow-up appointments for several years. These appointments come with regular surveillance scans — usually an X-ray or MRI of the treated area, and a CT of the chest, sometimes a PET scan — and they are also your standing opportunity to raise any concern with the treating team.

The schedule is deliberate: appointments are closer together at first and spread out over time. Follow-up this long is not a sign of worry about you personally; it is how sarcoma care is done, because finding any recurrence early gives the most options.

**If something changes between appointments** — a new lump, new pain, or you simply want to be seen sooner — do not wait for the next scheduled visit. Contact your clinical nurse consultant and an earlier review can be arranged.

## Your body, and how you feel about it

Cancer treatment and surgery often change your body: scars, weight change, hair loss during chemotherapy, or bigger changes after major surgery. It is normal to find these changes difficult — physically and mentally — and adjusting takes time.

Take it seriously if the way you feel about your body starts interfering with the way you want to live: being reluctant to leave home, withdrawing from people, avoiding intimacy with a partner, or persistent low mood. These are common, and they respond to support. Speak to the psychologist during your stay, your CNC, or your GP about seeing a mental health professional after you go home. This is part of treatment, not an extra.

## Palliative care — what the words actually mean

At some stage your specialist may suggest involving the palliative care team. **This is not the same as end-of-life care**, and a referral does not mean bad news. These teams now step in far earlier for anyone living with cancer, and their purpose is to help you live as fully as possible — above all by keeping pain and other symptoms under control. Their support can be given at home, in hospital, or wherever else suits you.

## Your decisions

Treatment is always your choice. You may decide not to have a particular treatment, or to have only treatment that reduces pain and discomfort. If you are weighing a decision like that, talk it through with your healthcare team, your GP, and your family or carer — you will be supported, not argued with.

## Support — people worth calling

Start with your **clinical nurse consultant or doctor**: they can answer questions about your own diagnosis and connect you with a psychologist or other support.

- **RPA Virtual Hospital — Sarcoma & Tumour Advice and Support Service (24/7):** 1800 463 918
- **RPA Sarcoma Clinic:** (02) 9515 1960
- **Cancer Council:** 13 11 20 — specially trained staff who can explain treatment, and link you to support groups and community resources
- **Cooper Rice-Brading Foundation** (sarcoma-specific support): crbf.org.au
- **Rare Cancers Australia:** rarecancers.org.au
- **Redkite** (support for children and young people with cancer): redkite.org.au
- **Canteen / Youth Cancer Services:** canteen.org.au
- **Translating and Interpreting Service (TIS):** 13 14 50
- **Carers Association (support and advice for carers):** 1800 242 636
- **Can Assist** (country NSW patients): canassist.org.au

**SOURCES**

1 RPA Bone and Soft Tissue Tumour & Sarcoma Patient Booklet, Royal Prince Alfred Hospital

2 Cancer Council — support services — https://www.cancercouncil.com.au/get-support/

3 Carer Gateway (Australian Government) — https://www.carergateway.gov.au/

# For family and carers

If someone you love is being treated for sarcoma — how to help at appointments and in hospital, the practical supports available to you, and permission to look after yourself too.

A sarcoma diagnosis lands on a whole household, not one person. If you are the partner, parent, child or friend doing the driving, the waiting and the worrying, this page is for you. The rest of this guide is written for the patient; everything in it may also be read by you — and it helps enormously when families understand the plan too.

## At appointments

Come. Patients are encouraged to bring a family member or friend to every appointment. There is a great deal of information at each visit, and two sets of ears reliably catch more than one.

Practical things that help:

- Keep a notebook (or a phone note) of questions between visits, and bring it
- Write down what is said — especially names, dates and next steps
- Ask the team to explain anything again. Nobody minds. It is far better than going home unsure
- If English is not your family's first language, ask for a healthcare interpreter — it is free, and the team can arrange it for any appointment

## In hospital

Someone from the medical team sees the patient every day, and the **consultant surgeon makes the decisions about care**. If the family has concerns, a time can be arranged for the medical team to sit down and answer questions properly — ask the nurse looking after your person, the Nursing Unit Manager, or the clinical nurse consultant (CNC).

The CNC is the coordination point for the whole journey and is used to hearing from families, not just patients. For anything after hours, the **RPA Virtual Hospital sarcoma support line (1800 463 918)** is available 24/7 — explicitly for carers and family members as well as patients. In an emergency, always call 000.

## The practical load

- **Travel and accommodation.** If you are coming from more than 100 km away, the IPTAAS scheme subsidises travel and accommodation for the patient and, in many cases, an escort. The social work team can help you apply. Nearby accommodation can be arranged — speak to the CNC or call the RPA Accommodation Officer on 0407 672 351.
- **Parking** concessions are available for carers of patients attending ongoing cancer treatment — see the hospital-stay page for how to have the form validated.
- **Money and logistics.** The social worker's role explicitly includes helping families: financial support, transport, caregiver support and community services. You do not need to have everything worked out before asking.

## Looking after yourself

Carers get tired, frightened and burnt out — usually while insisting they are fine. Support for you is part of the system, not an indulgence:

- **Carer Gateway** (Australian Government): carergateway.gov.au — practical services, counselling and respite
- **Carers Association:** 1800 242 636
- **Cancer Council:** 13 11 20 — support for families and friends, not only patients
- The hospital's **psychology service** may also be able to support loved ones who are carrying their own emotional load through a family member's treatment — ask the CNC

One sentence worth keeping: *you cannot pour from an empty cup.* Accept the offers of help, share the driving, and see your own GP if your sleep, mood or health starts to slip. The person you are caring for needs you well more than they need you selfless.

**SOURCES**

1 RPA Bone and Soft Tissue Tumour & Sarcoma Patient Booklet, Royal Prince Alfred Hospital

2 Carer Gateway (Australian Government) — https://www.carergateway.gov.au/

3 Cancer Council — Caring for Someone with Cancer — https://www.cancercouncil.com.au/cancer-information/family-and-friends/