ALK Positive Lung Cancer (UK)

# What Happens Next

## A guide for the transition to palliative care

*This guide was produced to help people navigating the transition from active cancer treatment to palliative care. It was written by someone who has lived this and found the gap between oncology and community care harder than it needed to be. It is intended to be adapted for your local area. If you are a healthcare professional or a charity and would like to use or build on it, please do.*

*We acknowledge that this guide is based on one produced by Amanda Arrowsmith.*

## A word before you begin

If you are reading this, you have just received news that changes everything. The team who have supported you, the routine of appointments and treatment, the familiarity of the oncology ward: all of that shifts, often very quickly. It can feel like the rug has been pulled from under you at the exact moment you need most support.

This guide will not make that easier. But it is intended to make the practical side a little less bewildering. It explains what has changed, who is now responsible for your care, what you are entitled to ask for, and who to call when you need help.

## What has changed

During treatment, your oncology team were the centre of your care. You had a clinical nurse specialist, a consultant, a route in. You knew who to contact and how.

That model does not continue into palliative care. This is not a failure of the system. It is a different phase, requiring a different kind of support. But it is a significant shift, and it is reasonable to feel unsupported when it happens without explanation.

Here is what the new structure looks like:

| During active treatment | In palliative care |
|---|---|
| **Oncology consultant leads your care** | Your GP leads your care |
| **Clinical Nurse Specialist as your named contact** | District Nursing team for clinical care at home |
| **24/7 oncology helpline** | 111 for urgent advice; hospice helpline if referred |
| **Regular outpatient appointments** | GP and community-based appointments |
| **Treatment focus: managing the disease** | Care focus: managing symptoms and quality of life |

Your oncology team will write to your GP with a full summary of your treatment and current situation. You are entitled to ask for a copy of this letter.

You may also receive support from the Enhanced Supportive Care team at the hospital who will work alongside your oncology team, GP and clinical nurse specialist.

## Who does what

### Your GP

Your GP is now the lead clinician for your care. They can prescribe medication, make referrals, arrange for specialist input and coordinate your support. If you have not already done so, request an appointment specifically to discuss your situation (not a routine appointment). Ask to be registered on the palliative care register, which ensures your GP practice prioritises your care and flags your records for out-of-hours services.

### District Nursing team

District Nurses provide clinical care in your home: wound care, medication management, syringe drivers, catheter care and more. Your GP refers you. Once referred, you will have a named district nurse, and the team can visit at home. They are not on call 24 hours but do have an out-of-hours service, and you will be able to confirm the contact number when you are first seen.

### Macmillan nurse

Macmillan nurses are specialist palliative care nurses, usually based in the community or at the hospice. They offer expert symptom management advice and emotional support. They do not replace your district nurse but provide specialist clinical input alongside them.

### Your local hospice

Hospices provide much more than in-patient end of life care. Most offer day hospice, outpatient clinics, therapy services, symptom management and family support, often while you remain at home. Referral is usually via your GP or Macmillan nurse. There is no charge for hospice care.

### Maggie’s

Maggie’s offers free practical, emotional and social support to people with cancer and those who care for them. You can drop in without an appointment.

## Questions worth asking at your first GP appointment

You do not have to ask all of these, but having them written down means you can hand the list to your GP if you run out of words.

- Can you register me on the palliative care register?
- Who is my named GP for palliative care?
- Can you refer me to the District Nursing team?
- Can you refer me to a Macmillan nurse?
- Can you refer me to the hospice for day services or outpatient support?
- Can I have a copy of the letter from my oncology team?
- How do I manage my medication from here? Who will prescribe it?
- What do I do if symptoms change or worsen at night or at a weekend?
- Can I have a just-in-case medication box at home?
- Who should I call first if I need urgent help?
- Can my carer get a carer’s assessment?
- What am I entitled to in terms of financial support?

### A note on just-in-case medication

A just-in-case (anticipatory) medication box is a small supply of medication kept at home to manage symptoms quickly if they arise: pain, breathlessness, agitation, nausea. You do not have to be at the end of life to have one. Ask your GP or Macmillan nurse about it.

## Practical things to sort now

### Prescriptions

Ask your GP about a repeat prescription arrangement. If you are entitled to free prescriptions (which you are if you have a terminal illness), apply for a medical exemption certificate. Ask your GP surgery for form FP92A.

### Equipment

Equipment to support care at home (a hospital bed, rails, a wheelchair, a commode) is available via your District Nursing team or an Occupational Therapist (OT). Speak with your GP about an OT assessment if you need one.
Equipment is provided free through the NHS. It can take time to arrive, so if possible request it before you think you need it.

### Financial support

You may be entitled to financial support you are not currently receiving:

- Personal Independence Payment (PIP), or Disability Living Allowance if the patient is under 16. Apply via the DWP; use the DS1500 fast-track route for terminal illness (your GP can provide this).

- Attendance Allowance, for those over 65.
- Carer’s Allowance, for anyone spending 35 or more hours a week caring.
- Council Tax reduction, if the patient is severely mentally impaired or if the carer lives with them.
- Macmillan grants: one-off financial assistance for people with cancer. Ask your Macmillan nurse or call the Macmillan helpline.

Maggie’s can help you navigate benefits if it feels overwhelming, or Citizens Advice. Many hospices and Macmillan centres also have benefits advisers. If you or your partner is part of the Armed Forces community, The Royal British Legion may also be able to assist with benefits, debt and money advice..

## Advance care planning and ReSPECT

This covers your wishes: where you would like to be cared for, what treatments you would or would not want, and who should be involved in decisions if you cannot make them yourself. You do not have to do this immediately or all at once. But starting the conversation with your GP or Macmillan nurse early means your wishes are known, recorded and travel with you across care settings.

Documents to be aware of:

- Advance Statement: your preferences and wishes (not legally binding but taken seriously by all who care for you)
- Advance Decision to Refuse Treatment (ADRT): a legally binding refusal of specific treatments
- Lasting Power of Attorney (LPA) for Health and Welfare: appoints someone to make decisions on your behalf if you lose capacity to do so yourself
- ReSPECT form: a personalised summary of your care and treatment wishes for use in an emergency (see below)
- Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form, completed with your clinical team

### The ReSPECT process

ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment. It is used across Gloucestershire and is a form completed through conversation between you, your family and your clinical team. It records what matters most to you, what treatments you would and would not want in an emergency, and your preferred place of care.

ReSPECT is broader than a DNACPR form, which only covers resuscitation. ReSPECT covers the full picture of your emergency care preferences and travels with you across all care settings, so that if you are admitted to hospital, treated at home or seen by paramedics, your wishes are already known.

### A note on Lasting Power of Attorney

A Lasting Power of Attorney (LPA) for Health and Welfare gives someone you trust the legal authority to make decisions about your care and treatment if you are no longer able to make them yourself. It can only be set up while you have mental capacity to do so.

If this is not already in place, it is worth acting on promptly. Your solicitor can help, or you can register one yourself via gov.uk. There is a registration fee, and it takes several weeks to process. Do not wait until you think it is needed.

## If things change quickly

If something happens, knowing who to call, and in what order, can reduce the panic when symptoms change suddenly.

| Situation | Who to call |
|---|---|
| Symptoms have changed or worsened (in hours) | Your Macmillan nurse or District Nurse (in hours) |
| Symptoms have changed (out of hours) | GP out-of-hours or hospice advice line |
| Urgent medical advice needed | 111 |
| Life-threatening emergency | 999 |
| Emotional support, any time | Macmillan helpline |
| Hospice advice (once referred) | Hospice 24-hour line |

## What if I am caring for someone who is moved to palliative care?

This section is for you. If you are caring for someone with a terminal illness, your needs matter too, and they are recognised in law.

### Carer’s assessment

You are entitled to a carer’s assessment from your local authority, regardless of how many hours you care, how much the person you care for needs, or whether you live with them. The assessment looks at the impact caring has on your life and what support might help. Contact your local adult social care team to request one.

### Carer’s Allowance

If you spend 35 or more hours a week caring, you may be entitled to Carer’s Allowance. Check eligibility and apply at gov.uk or via Citizens Advice.

### Your own GP

Tell your own GP that you are a carer. They can flag this on your records, prioritise your appointments and ensure you are not overlooked. Carers are at higher risk of physical and mental health difficulties; looking after yourself is part of caring well.

### Support for you

- Maggie’s offers support for family members and carers as well as patients.
- Hospices provide family support and counselling; ask what is available.
- Carers UK has a helpline and online forum: 0808 808 7777.
- Marie Curie’s Helper service can provide a volunteer to sit with your loved one so you can take a break.

|  | Phone | What they offer |
|---|---|---|
| Macmillan Support | 0808 808 00 00 | Free helpline 8am to 10pm, 7 days. Benefits advice, emotional support, local services. |
| Marie Curie | 0800 090 2309 | Free helpline, palliative care information, Helper volunteer service. |
| Hospice UK | 020 7520 8200 | Information on hospice services across the UK. |
| Carers UK helpline | 0808 808 7777 | Advice and support for carers. Monday to Friday, 9am to 6pm. |
| Sue Ryder Online | 0808 164 4572 | Bereavement support and end of life care information. |
| Citizens Advice | 0800 144 8848 | Benefits, financial and legal advice. |
| 111 | 111 | Urgent medical advice when your GP is closed. |

## Useful booklets and resources

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|---|---|
| **The following guides can be downloaded or ordered free of charge. Scan the QR code next to any title to open it directly on your phone.** | A Guide for the End of Life<br>Practical and emotional guidance for patients and families as treatment ends. |
| Your life and your choices: plan ahead<br>**Information on advance care planning, palliative care, and making decisions ahead of time.** | What to expect at the end of someone’s life<br>An honest, clear guide to what the final weeks and days may look like. |
| Caring for someone at home<br>**Practical advice for carers on managing day-to-day care at home.** | Being cared for at home<br>Written for the person receiving care; what to expect and how to get the most from support. |

## Your checklist

Work through this when you can. You do not have to do everything at once. Tick things off as you go.

### Your GP and care team

☐ Book a GP appointment to discuss your transition to palliative care
*Ask specifically for a longer appointment, not a routine slot*

☐ Ask to be registered on the palliative care register

☐ Ask your GP to refer you to the District Nursing team

☐ Ask your GP to refer you to a Macmillan nurse

☐ Ask your GP to refer you to the hospice for day services or support

☐ Request a copy of the handover letter from your oncology team

☐ Ask about a just-in-case (anticipatory) medication box at home

☐ Confirm out-of-hours numbers for all your care contacts
*Fill these in on your contacts page*

### Practical and financial

☐ Apply for medical exemption certificate for free prescriptions
*Ask your GP surgery for form FP92A*

☐ Request an Occupational Therapist assessment for home equipment

☐ Check benefit entitlements
*PIP or Attendance Allowance, Carer's Allowance, Council Tax reduction, Macmillan grants*

☐ Contact Maggie's, Citizens Advice, Macmillan or a hospice benefits adviser for help with benefits

### Advance care planning

☐ Complete a ReSPECT form with your GP, District Nurse or Enhanced Support Team

☐ Set up a Lasting Power of Attorney for Health and Welfare if not already in place
*Act promptly; it can only be done while you have mental capacity*

☐ Consider an Advance Statement and/or Advance Decision to Refuse Treatment (ADRT)

### Support and connections

☐ Visit or contact Maggie's

☐ Request a carer's assessment for yourself or your carer
*Contact your local adult social care team*

☐ Tell your own GP that you are a carer