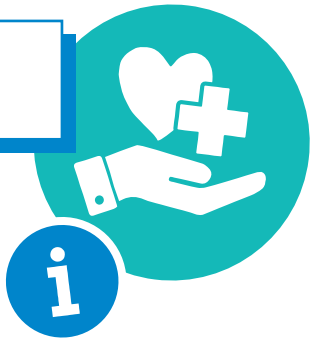
Advanced therapies (ATMPs)

A self-advocacy guide for people affected by cancer



This resource is for people affected by cancer who want to understand whether advanced therapies, including Advanced Therapy Medicinal Products (ATMPs), may be an option for them now or in the future.

Its purpose is to help you feel more informed and prepared for conversations with your healthcare team. It doesn't replace medical advice, but it can help you ask questions, share what matters to you, and understand the choices being discussed.

You have the right to ask about your treatment options and to be part of decisions about your care. This includes asking whether an advanced therapy, clinical trial or referral to a specialist centre could be appropriate for your type of cancer, your health, your values and your personal circumstances.

How to use this guide

You may want to take this guide to an appointment, highlight the questions that matter most to you, or use it when speaking to a specialist nurse, consultant, GP, support line nurse or clinical trials team. You do not need to ask every question at once. Start with what feels most important or most urgent for you.

You can also ask someone you trust to come with you, take notes, remember what was said, or help you follow up afterwards. It is okay to ask for information to be repeated, written down or explained in a different way.



What are ATMPs?

Advanced Therapy Medicinal Products, usually shortened to ATMPs, are newer types of treatment that use genes, cells or tissues in ways that are different from many traditional medicines. Depending on the treatment, they may aim to repair, replace, regenerate or re-engineer parts of the body so that normal function can be restored or improved.

Some ATMPs are already used for particular cancers, including certain blood cancers and some other cancer types. Others are being studied through clinical trials. An ATMP will not be right for everyone, and this is not your fault. Suitability depends on things such as your diagnosis, previous treatment, general health, what is approved or available, and what feels acceptable to you.

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Why might I not hear about ATMPs automatically?

You may not hear about ATMPs automatically, even when you are actively looking for options. This can happen because awareness is still developing and because your healthcare team may need to check whether a therapy is approved for your condition, available in Wales or elsewhere in the UK, open through a clinical trial, or accessible through a specialist referral.

Some advanced therapies are delivered only in specialist centres because they can involve complex preparation, short shelf lives, close monitoring and specific follow-up care. It is reasonable to ask what this could mean for you in practical terms, including travel, time away from home, hospital stays, family or caring responsibilities, and support after treatment.

Conversation starters

If you are not sure how to begin, you could use one of these phrases or adapt it into words that feel natural to you:

- I have heard about advanced therapies and would like to understand whether any could be relevant to my cancer and my situation.
- Can we talk through all the treatment options that may be available to me, including newer treatments and clinical trials?
- If an advanced therapy is not right for me at the moment, can you explain why and whether this might change later?
- Is there someone else, such as a specialist nurse, pharmacist, trials team or specialist centre, who I should speak to?

Questions to ask your healthcare team



Understanding my options

- Are there any new treatments for my type of cancer, including advanced therapies or clinical trials?
- What is the aim of this treatment, and what might it mean for my everyday life?
- How does this treatment differ from other treatments I have already had or could have?
- What evidence is available about how well this treatment works?

Suitability and eligibility

- Would this treatment be suitable for me, taking account of my cancer, my health and what matters most to me?
- Who decides whether I am eligible?
- What tests or assessments would be needed?
- If I am not eligible now, could that change later?
- Could I be considered for a clinical trial?

Access, referral and travel

- Is this treatment available in Wales, or would I need to travel to a specialist centre elsewhere in the UK?
- What is the referral process?
- How long might I wait for an assessment or decision?
- How often would I need to travel, and would I need to stay in hospital?
- What practical support is available for travel, accommodation, work, family life or caring responsibilities?

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Risks, side effects and follow-up

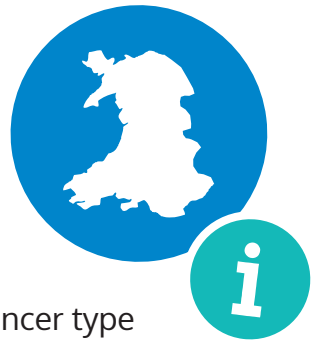
- What are the likely side effects, and are they short-term or long-term?
- What symptoms should I look out for after treatment?
- Who should I contact if I feel unwell or have questions afterwards?
- What follow-up appointments will I need, and where will they take place?
- How could this treatment affect my day-to-day life, including work, family, caring responsibilities, diet, driving, social contact and the things that are important to me?

If an ATMP is not suitable for me

Being told that an advanced therapy is not suitable can feel disappointing, frustrating or confusing. You are allowed to ask for a clear explanation, time to process the information, and support to understand what other options may be available.

- Can you explain why this treatment is not suitable for me?
- Are there other treatments, trials or supportive care options I should know about?
- Could my case be reviewed by a specialist multidisciplinary team?
- Would a second opinion or referral to another specialist centre be appropriate?
- When should we revisit this conversation?

ATMPs in Wales



The Advanced Therapies Wales programme was established by Welsh Government in 2019 and has an all-Wales remit. Approved advanced therapies should be available to eligible Welsh patients, although not all are delivered within Wales. If treatment would involve travelling to a specialist centre elsewhere in the UK, you can ask what support may be available and how this would fit around your needs and responsibilities.

ATMPs may be most relevant where they're already approved for a particular cancer type or where a clinical trial is available. Your healthcare team can explain whether this applies to your diagnosis and help you understand the possible benefits, risks and practical impact for you.

Reliable sources of information

It can be helpful to use reliable information alongside advice from your own NHS healthcare team. You may want to look at information from Advanced Therapies Wales, the Advanced Therapy Treatment Centre Network, Cancer Research UK and Macmillan Cancer Support. If something you read online sounds relevant, take it to your healthcare team and ask whether it applies to you.

- **Advanced Therapies Wales** | advancedtherapieswales.co.uk
- **Advanced Therapy Treatment Centre Network** | theattcnetwork.co.uk/patients-and-public
- **Cancer Research UK: CAR T-cell therapy** | cancerresearchuk.org/about-cancer/treatment/targeted-cancer-drugs-immunotherapy/car-t-cell-therapy
- **Macmillan Cancer Support: Questions to ask your healthcare team** | macmillan.org.uk/cancer-information-and-support/treatment/your-treatment-options/questions-to-ask-your-healthcare-team

Before your appointment

Before speaking to your healthcare team, you may want to write down your diagnosis, treatments you have already had, what matters most to you, what support you have at home, and the questions you most want answered. Bringing this with you can help make sure the conversation focuses on your priorities as well as the medical options.

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