Navigating Transitions in Care

A practical leaflet for patients and carers | RDW-01-12

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A transition in care happens when some or all of your care moves between professionals, services or settings. This may mean leaving hospital, moving to adult services, changing specialist teams or relocating. This leaflet helps you prepare, clarify responsibilities and check the next steps. Services are responsible for a safe handover; patients and carers should not be left to organise it alone. [1]

A handover needs more than a referral

A referral asks another service to assess or treat you. A handover transfers relevant information and responsibility. Ask which team is taking over, what it has agreed to do and when responsibility changes. A letter being sent does not necessarily mean a referral has been accepted or an appointment arranged.

For a rare or undiagnosed condition, ask how the new team will obtain specialist advice. Clarify which care stays with your existing clinicians and which moves. Do not assume that every team uses the same electronic record or has access to all previous results.

Agree a named contact and a written plan

Ask who coordinates the move, who covers their absence and who to contact if arrangements do not happen. For hospital discharge, this may be a discharge coordinator. Request a plan in a format you can use, with clear responsibilities and follow-up arrangements. [2]

- Which service is responsible before, during and after the move?
- When is the first appointment or review, and who will arrange it?
- Who will deal with outstanding results, prescriptions and monitoring?
- What support, equipment or training must be ready?
- Who can I contact with concerns, including outside normal hours?

Bring the information that matters

Ask teams to share a dated clinical summary, current treatment plan, relevant results and any clinician-verified emergency instructions securely. Keep your own copy where possible. Include allergies and reactions, communication needs, equipment and what matters most to you. Mark suspected diagnoses separately from confirmed ones and tell the new team if information is incorrect.

You do not need to repeat your entire history at every appointment. A short personal summary can help, but it supports rather than replaces professional records and direct communication between teams.

Medicines and leaving hospital

Check medicines when care changes

Medicines reconciliation means a healthcare professional compares what you actually take with the recorded lists and resolves differences. Ask for an accurate list when you move between services. Include prescribed and non-prescription medicines, supplements and herbal products, with their names, strengths, doses and timings. [3]

For every medicine started, changed or stopped, ask why and when the change takes effect. Confirm who will prescribe the next supply, arrange blood tests or other monitoring and act on the results. Ask a pharmacist or prescriber to resolve conflicting instructions rather than choosing between them yourself. [3]

Check that you can obtain the next supply before it is needed, including specialist or home-delivered treatments. If you are running short, contact the responsible service promptly. Do not ration, stop or change a prescribed treatment without advice.

Before you leave hospital

Ask for a discharge summary explaining why you were admitted, the treatment given and the next steps. Confirm that your usual clinician and relevant services will receive it. Check who owns any pending results or referrals, even if you are otherwise ready to leave. [2]

The plan needs to work where you will be living. Tell the team about access difficulties, food or personal-care needs, travel problems and what your carer can realistically provide. Ask for training if you or a carer will use equipment, manage dressings or carry out other care. Confirm that essential support will be available. [4]

A checklist for the day of the move

☐ I have the written plan, clinical summary and current medicines list.

☐ I know who to contact and what symptoms or problems need urgent help.

☐ I know the next appointment and who will follow up outstanding results.

☐ The medicines, equipment and support I need have been arranged.

☐ I understand any care tasks, or know who will help with them.

If something essential is missing, tell the ward or transition team before the move and ask them to explain how the gap will be managed. Say back the plan in your own words so the team can check that it has explained things clearly. [4]

Moving services and settling in

From children's to adult services

Transition is the process of preparing for adult care; transfer is the actual move. Ask to plan ahead around the young person's needs, understanding and readiness, as well as local service rules. There is no single transfer age or pathway that applies internationally. Ask for a named worker and, where possible, a meeting with the receiving team before transfer. [5]

Agree the young person's role in appointments, medicines and decisions at a manageable pace. Discuss whom they want involved and how parents or carers can continue to help. Consent, confidentiality, decision-making support and carers' legal authority may change; ask the services to explain the rules that apply locally. [5]

If no equivalent adult service exists, or eligibility changes, ask for a specific alternative plan rather than an open-ended discharge. Include education, work, social care and emotional support where relevant. Someone who needs help managing care should not be expected to become independent overnight. [5]

Changing providers or moving country

Check whether a fresh referral, registration, funding approval or assessment is needed. Ask the receiving service to confirm acceptance and how to obtain prescriptions while you wait. Check medicine availability, costs and permitted supply arrangements before travelling; a prescription or treatment approval may not transfer between countries.

Arrange secure transfer of records and translations where needed. Ask who will coordinate with specialist services, homecare suppliers and community support. If there may be a gap, request a bridging plan from the current and receiving teams. Do not assume your previous service can continue prescribing after you move.

Check the plan after arrival

Confirm that the new service has the records it needs, that appointments and supplies are in place and that you understand any changes. Keep a brief note of unresolved actions and the team responsible. If an expected contact does not happen, use the agreed contact details and ask for an update.

If the problem remains unresolved, ask for the service manager, transition coordinator or patient advice or advocacy service. Local routes differ. Seek clinical advice promptly if the gap affects treatment or your health; a complaints process is not a substitute for urgent care.

Key points

Know who is taking over and when. Check medicines, monitoring, pending results and practical support before the move. Keep a usable written plan and ask for help if it is not workable. A transition is complete when the necessary care is in place, not simply when a letter has been sent.

Ask your clinical team to verify your personalised emergency and medicine instructions. If you become severely or rapidly unwell, contact local urgent or emergency services rather than waiting for a routine appointment or administrative reply.

References and further reading

Sources are numbered in order of first mention. Select a title to open its source URL. Sources checked on 3 November 2026. Guidance from individual countries informs these practical suggestions; local pathways, rights and funding may differ.

1. Australian Commission on Safety and Quality in Health Care. Transitions of care

2. National Institute for Health and Care Excellence. Transition between inpatient hospital settings and community or care home settings for adults with social care needs NG27 recommendations

3. National Institute for Health and Care Excellence. Medicines optimisation NG5 recommendations

4. US Agency for Healthcare Research and Quality. Care Transitions From Hospital to Home IDEAL Discharge Planning

5. National Institute for Health and Care Excellence. Transition from children's to adults' services for young people using health or social care services NG43 recommendations

Applying this information

Clear responsibilities, accurate medicines information and planned communication are established safety principles. This leaflet does not show that a checklist alone prevents problems or that one transition model suits every rare condition. Some guidance cited concerns specific groups, such as adults with social care needs or young people moving to adult services.

The responsible teams need to confirm the individual plan, clinical risks, medicine supply, equipment, monitoring and urgent-care arrangements. Consent, decision-making authority, record sharing and cross-border access require confirmation under the rules where care is provided.

Share personal health records only through an agreed secure route. You do not need to send medical information to Rare Disease Watch to use this leaflet.

https://rarediseasewatch.com/

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