# Life after Severe Pancreatitis

## Recovery, Rehabilitation and Support

> Recovering from a severe episode of acute pancreatitis does not end when you leave hospital. Many people who have had a long hospital admission (particularly those who spent time in intensive care or high dependency) find that the weeks and months afterwards bring their own challenges: physical, psychological, and nutritional. This leaflet can help you prepare for what to expect during this recovery period, the support available, and when you should seek help. It is general information and does not replace advice from your own clinical team, who understand your particular illness and circumstances.

## Why recovery takes time

It is normal for recovery from severe acute pancreatitis to take considerably longer than the hospital stay itself. As a general guide, full recovery can take at least three times as long as the length of your admission. So, for example, a four-week hospital stay might be followed by three months or more of ongoing recovery before you feel back to yourself. Progress is not always a straight line: some people have setbacks, a slower patch or readmission, and further treatment may be needed for a complication that only becomes apparent after discharge. This is a recognised part of recovery, not a sign that something has gone wrong.

## The effects of a long hospital stay

A prolonged hospital admission, especially one involving a period of critical illness or intensive care, takes a physical toll that continues well after discharge. This collection of physical, mental and emotional effects is sometimes called post-intensive care syndrome, though milder versions can follow any long, serious illness.

- **Muscle weakness and wasting**: time spent immobile in a hospital bed, particularly during critical illness, causes significant loss of muscle strength, sometimes called ICU-acquired weakness. This can make everyday tasks (climbing stairs, carrying shopping, standing from a chair) feel much harder than before your illness.
- **Fatigue**: persistent tiredness that goes beyond normal tiredness, and can take weeks or months to fully improve.
- **Breathlessness and reduced fitness**: particularly if your lungs were affected during your illness or you needed a ventilator.
- **Sleep disturbance**: unusual sleep patterns, vivid dreams, or difficulty sleeping are common for a while after a hospital stay.
- **Reduced mobility and balance**: which increases the risk of falls, especially early in recovery.

Physiotherapy and occupational therapy (often started in hospital and continued afterwards) are central to rebuilding strength and confidence. Recovery is generally best approached gradually: build up activity a little

at a time, allow rest days, and avoid the temptation to do too much on a good day, which can lead to a setback the next. Ask your team about a structured rehabilitation programme if one is available in your area.

If you were in a physically demanding job, or your work involves lifting, prolonged standing, or shifts, a phased return to work (with input from your GP and, where available, occupational health) is usually more successful than returning all at once.

## Psychological effects

It is very common to experience psychological effects after a severe illness, particularly one involving intensive care, and these are just as real and important as the physical effects. They are not a sign of weakness, and you are not alone in experiencing them.

- **Anxiety and low mood**: including worry about your health, your future, or a recurrence episode.
- **Memory loss**: it is common to not remember periods of your treatment or what happened to you, especially if you were in intensive care and had episodes of delirium or confusion.
- **Flashbacks, nightmares, or intrusive memories**: some people experience symptoms similar to post-traumatic stress disorder (PTSD) after a critical illness, including distressing memories of their time in hospital (sometimes including frightening or confused memories from periods of delirium or sedation), or avoidance of reminders of the experience.
- **Difficulty concentrating or "brain fog"**: problems with memory, concentration or thinking clearly are common for a period after critical illness and usually improve with time.
- **Changes in how you feel about your body**: particularly if you have new scars, a wound that is still healing, a stoma, or feeding tube, or if your weight or shape has changed.
- **Strain on relationships and family**: a severe illness affects partners, children and carers too, who may have their own worries or exhaustion from the experience.

These difficulties often improve on their own over time, but for some people they persist or significantly affect daily life. Please tell your team if you are experiencing any of this. Support is available and effective, including talking therapies (such as cognitive behavioural therapy), counselling, peer support from others who have been through critical illness, and, where appropriate, medication. Ask your GP or hospital team about a referral, or about self-referring to talking therapies services in your area.

## Nutritional issues

Severe pancreatitis and a long hospital stay commonly lead to significant weight loss and muscle loss, and rebuilding nutrition is a key part of physical recovery. Several specific issues are worth being aware of:

- **Reduced appetite**: it is common for your appetite to take time to return to normal; eating small, frequent meals is often easier than three large ones while this recovers.
- **Pancreatic exocrine insufficiency**: if your pancreas is not producing enough digestive enzymes, you may have ongoing weight loss, bloating, or pale, oily, foul-smelling stools; this is treated with pancreatic enzyme replacement therapy (PERT). See our "Nutrition in Pancreatitis" leaflet for detail on how PERT works and how to take it correctly.
- **Diabetes**: new or worsening diabetes can follow severe pancreatitis; your blood sugar will usually be monitored for a period after discharge, and you may need input from a diabetes team.

- **Vitamin and mineral deficiencies**: particularly of the fat-soluble vitamins A, D, E and K, if fat digestion has been affected; these are checked with blood tests and corrected if low.
- **Protein intake for muscle recovery**: eating enough protein (from sources such as lean meat, fish, eggs, dairy, or pulses) supports rebuilding the muscle lost during your illness, alongside physical rehabilitation.

A dietitian is an important part of your ongoing care and can help tailor nutritional advice to your particular situation, including if you need enzyme replacement, tube feeding support after discharge, or simply help getting your weight and appetite back on track.

## Who can help during your recovery

Recovery after severe pancreatitis often benefits from input from several different people. You do not need to manage this alone, and you can ask your GP or hospital team for a referral to any of the following:

| Who | Can help with |
|---|---|
| **Dietitian** | Nutrition, weight, enzyme replacement (PERT), vitamin levels |
| **Diabetes team** | New or worsening blood sugar control |
| **Pain management team** | Ongoing or difficult-to-control pain |
| **Physiotherapist / occupational therapist** | Rebuilding strength, mobility, and daily function |
| **Psychologist or counsellor** | Anxiety, low mood, flashbacks, or difficulty adjusting |
| **GP** | Overall coordination, sick notes, general concerns, first point of contact |
| **Alcohol or smoking cessation services** | Support to stop drinking or smoking |
| **Surgical / gastroenterology team** | Ongoing complications, further procedures, follow-up scans |

## Other practical considerations

- **Wounds, drains and stomas**: if you had surgery or drains during your admission, you should have clear instructions on wound care and a contact number if you have concerns; a district nurse or wound clinic can help if healing is slow.
- **Alcohol**: if alcohol played any part in your illness, continued support to stay abstinent is one of the most important things you can do to protect your recovery and prevent a further episode.
- **Smoking**: stopping smoking supports both your general recovery and your pancreas specifically; ask about local stop-smoking services.
- **Driving**: check with your team and your insurer before returning to driving, particularly after a hospital stay involving surgery, sedation, or new medication.
- **Follow-up appointments and scans**: you will usually be offered follow-up to check your recovery, monitor for any late complications (such as a persisting fluid collection), and review your nutrition and blood sugar; try to keep these appointments even if you are feeling well.
- **Peer support**: other charities such as Guts UK and the Pancreatitis Supporters Network provide information and put people in touch with others who have been through similar experiences, which many

people find valuable alongside their clinical care.

## When to seek help or go back to your hospital team ("represent")

- New or worsening abdominal pain, especially if it feels similar to your original illness
- Fever, shivering, or feeling suddenly much more unwell
- Yellowing of the skin or eyes, dark urine, or pale stools
- Persistent vomiting, or an inability to keep food or fluids down
- A wound, drain site, or stoma that becomes red, painful, swollen, or starts leaking
- Symptoms of a blood clot: new swelling, pain or redness in a calf, or sudden breathlessness or chest pain
- Rapid or continued weight loss despite following dietary and enzyme advice
- New symptoms of high or low blood sugar, such as excessive thirst, confusion, or sweating and shakiness
- Thoughts of harming yourself, or feeling unable to cope. These are medical emergencies just as much as physical symptoms, and urgent help is available

If in doubt, contact your GP, your hospital team's advice line, or NHS 111. If you feel it is a medical emergency, go to your nearest emergency department or call 999. Do not wait for your next scheduled appointment if you are worried.

## Key points to remember

- Recovery from severe acute pancreatitis usually takes considerably longer than the hospital stay itself, often three times as long, or more.
- A long hospital or intensive care stay commonly causes muscle weakness, fatigue and reduced fitness, which improve gradually with rehabilitation.
- Psychological effects (anxiety, low mood, flashbacks or difficulty adjusting) are common after severe illness and are not a sign of weakness; support is available and works.
- Weight loss, appetite changes, digestive enzyme deficiency and new diabetes are common nutritional issues; a dietitian is a key part of your ongoing care.
- Recovery is a team effort: dietitians, physiotherapists, psychologists, diabetes teams and your GP can all play a part; ask for referrals if you need them.
- Contact your team promptly for new or worsening pain, fever, jaundice, wound problems, signs of a blood clot, or if your mental health is struggling. Don't wait for your next appointment.

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