

# HOW TO LOOK AFTER YOURSELF IN HOSPITAL

A guide for patients in the era of coronavirus

by

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– SECOND EDITION –

There is a long tradition, in the English-speaking world and elsewhere, that it is not the duty of hospitals to encourage and empower patients to participate in decisions about their treatment. Doctors and managers can act as if patients aren't entitled or competent to have a say in those decisions. In England, during the coronavirus pandemic that kicked off in 2020, decision-making rules were introduced that might almost have been purposely designed to allow doctors to avoid seeing matters from a patient's point of view.

This wouldn't matter so much if hospitals were places of safety. But they aren't. They are places where you can catch infections from other patients; where bureaucratic routines can mean long waits for tests and assessments; and where being confined to bed for much of the day – albeit under the supervision of very caring and well-meaning ward staff – can leave your body and mind out of condition. To successfully come through all these adverse circumstances, you need to be able to look after yourself while you're there.

If you are in hospital, if you want to get home as soon as possible, and if you believe you should be able to ask questions about how you are being treated, this guide is for you. It is intended to help you understand what is going on, hold on to your sanity, challenge decisions about your treatment that don't seem to make sense ... and then, when you feel ready, escape!

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## 1. Background

The coronavirus pandemic that flared up in 2020 enabled doctors in acute hospitals in England to send away older patients not suffering from the virus, to make room for those who did have it. In the past, some over-65s have found it difficult to escape from hospital: now hospitals can't get them out quickly enough!

On August 21st, 2020, the UK Government published a new 'rulebook' which says you can be discharged from an acute hospital at very short notice if your score is zero on a checklist of medical criteria. But the checklist measures nothing about where you are on your road to recovery. And living on tenterhooks certainly won't help you get better.

Nor does the rulebook say anything at all about working with elderly patients living with frailty who are in need of acute care, although they are known to be especially vulnerable. What it creates is a modern-day form of 'pass the parcel', where the patient over 65 is the parcel.

Under the new regime, many patients will be able to leave hospital sooner than in the past. Acute hospitals are expected to send 95% of non-coronavirus patients directly home. It is said that another 4% will need rehabilitation or short-term care in a 24-hour bed-based setting, likely to be a local community hospital. In March 2020 these figures were assumptions: evidently they have already hardened into expectations. On this trajectory, they seem likely to acquire the status of targets soon, if they haven't already.

But nationwide expectations or targets like these take no account of the fact that the proportion of older people in the population varies widely across the country. In Cornwall, for example, the proportion of over-65s is half as much again as the proportion averaged across England. So the estimate of 4% needing rehabilitation or short-term care in a 24-hour bed-based setting could be a considerable under-estimate.

Even before the coronavirus pandemic, community hospitals were under huge pressure, with many patients staying on even after they were judged medically fit for discharge. Now they are set to really become the poor relations of the hospital world: unglamorous, full to bursting, and under-resourced. If you are over 65 and have broken something in a fall, such a hospital is where you could find yourself once the fracture has been operated on.

## 2. Before coronavirus and now: how the rules have changed

Before the coronavirus arrived, NHS England and Improvement (NHSE/I), the body that governs NHS hospitals, was paying attention to identifying frail elderly patients. Doing this within a few hours of their arrival at hospital 'enables prompt, targeted management based on a comprehensive geriatric assessment approach. It also allows screening and treatment to start with the appropriate skilled multidisciplinary team as soon as the patient arrives in hospital.'<sup>[1]</sup> But since the coronavirus arrived, there is a new 'rulebook' (see below) which makes no mention of frailty, and the comprehensive geriatric assessment has disappeared.

Again, before the pandemic NHSE/I used to say a patient was ready to go home when three conditions had been met: (1) a clinical decision had been made the patient was ready to leave;

(2) a multidisciplinary team decision – involving geriatricians, physiotherapists, occupational therapists, possibly carers and family – had been made that the patient is ready for transfer home, and (3) it was considered safe to discharge the patient home.<sup>[2]</sup> Now it takes only the clinicians – doctors – doing their checklist exercise for you to be ‘deemed suitable for discharge’. No multi-disciplinary team is involved in the decision to discharge, nor is safety of discharge to your home listed as a consideration.

### **3. Leaving the acute hospital: discharge arrangements under the ‘coronavirus rulebook’**

Details of the checklist exercise are contained in what I call the ‘coronavirus rulebook’. The original version was published by the UK Government in March 2020 under the title *COVID-19 Hospital Discharge Service Requirements*.<sup>[3]</sup> An updated version was published on 21 August 2020 as *Hospital Discharge Service: Policy and Operating Model*.<sup>[4]</sup>

The current, updated rulebook tells acute hospitals to operate something called the ‘discharge to assess pathways model’. (‘Discharge to assess’ means that any assessment of your need for continuing treatment or care will take place after you have been discharged: you don’t have to wait for it before you can leave the acute hospital.) This is based on ‘four clear pathways’:

Pathway 0: 50% of people – simple discharge, no formal input from health or social care needed once home.

Pathway 1: 45% of people – support to recover at home; able to return home with support from health and/or social care.

Pathway 2: 4% of people – rehabilitation or short-term care in a 24-hour bed-based setting.

Pathway 3: 1% of people – require ongoing 24-hour nursing care, often in a bedded setting. Long-term care is likely to be required for these individuals.’

The earlier version of the rulebook described this model rather differently. It said:

This model, based on best practice, assumes that: 50% of people can go straight home on discharge with minimal or no additional support; 45% can go straight home on discharge with a short or longer-term support care package; 4% will require rehabilitation support in a residential or nursing care setting; and 1% will require nursing home care.

As we can now see, the percentage breakdown is based on *assumptions*. Whoever revised the rulebook seems to have chosen to conceal this. But it means that hospitals are being told to apply assumptions irrespective of the age make-up of their catchment population. So this is a ‘one size fits all’ formula. In an area with a high proportion of retired people – like Cornwall, where one-quarter of the population are 65 or older, around half as much again as for England as a whole – there is the danger that the proportion who can’t go straight home may turn out to be significantly higher than 5%.

There is another danger, that the assumptions get treated as a ‘quota’, a set of targets. If, for example, 6% or 7% of patients have already been identified as in need of residential care that day or week, staff may be reluctant to add to their number if they fear they will be called to

account for exceeding their quota. If you are one of the excess patients, you may find yourself the unwitting subject of a game of 'pass the parcel'.

The current rulebook contains a list of criteria for discharge, said to have been developed in conjunction with the Academy of Medical Royal Colleges. The rulebook's instructions are not altogether clear. It sets out a three-stage 'discharge to assess model', in which Stage One (on Page 11) starts: 'Begin discharge planning from the point of hospital admission, including the identification of immediate needs of the individual at home following discharge.' It is difficult to see how this identification of needs can take place when a patient comes in with a broken limb, probably in pain and/or under sedation.

Stage One continues: 'Review each individual daily and identify people for discharge to leave that day.' More precisely, it goes on: 'Undertake daily clinically-led reviews of all people at a morning ward round. Any person [i.e. patient] not meeting the clinical criteria to reside [i.e. stay] will be deemed suitable for discharge.' The words used – 'identified', 'deemed' – seem to indicate that this is a judgment not open to challenge.

But in the rulebook's Annex A (on Page 39), where the criteria are presented as a list of questions, reproduced below, we read: 'Every person on every general ward should be reviewed on a twice daily ward round to determine the following. If the answer to each question is 'no', active consideration for discharge to a less acute setting must be made.' Giving 'active consideration to discharge' seems to leave some scope for deciding *not* to discharge.

**'Criteria to reside'** (*Hospital Discharge Service Policy and Operating Model, Annex A*)

- Requiring ITU or HDU care?
- Requiring oxygen therapy/NIV?
- Requiring intravenous fluids?
- NEWS2 > 3? (clinical judgement required in persons with AF and/or chronic respiratory disease)
- Diminished level of consciousness where recovery realistic?
- Acute functional impairment in excess of home/community care provision?
- Last hours of life?
- Requiring intravenous medication > b.d. (including analgesia)?
- Undergone lower limb surgery within 48hrs?
- Undergone thorax-abdominal/pelvic surgery with 72 hrs?
- Within 24hrs of an invasive procedure? (with attendant risk of acute life- threatening deterioration)

AF = atrial fibrillation; HDU = high dependency unit; ITU = Intensive Therapy Unit; NEWS = national early warning score; NIV = non-intravenous (?). Acronyms translated courtesy of NHS Confederation. [\[5\]](#)

Here are some things to notice about this checklist:

- There is no secret about the list, but it is not intended for your eyes.
- The language used is the special – ‘technical’ – language that members of the medical profession use to communicate with one another. It is not deliberately intended to be impenetrable to outsiders, but in practice it is.
- Entirely lacking from the list of questions is any sense of a dynamic, of movement, of development over time. **Not a single one of the questions is to do with your progress as a patient, how far you have got along your road to recovery.**

Notice in particular that the questions/criteria are all in the moment, the here-and-now. This is entirely consistent with the way that the NHS and the medical professions see the work of doctors, as a series of episodes. (The unit of work in the NHS is the ‘consultant episode’.) When one set of doctors in a hospital finish their shift and hand over to another, they hand over responsibility for the continuing care of their patients to the set taking over: consequently it may be that no doctor sees a patient’s path or ‘trajectory’ through the hospital from start to finish as a whole, as a single process from admission to departure. In effect, doctors are – by default – taught not to look ahead, all the way to the patient’s full restoration of health.

#### **4. Holding on to your sanity in an acute hospital**

What are the consequences for you of the way this system works?

First of all, before the discharge process comes into play, you and your family will have to be very strong-minded not to be on tenterhooks every morning while you’re in the ward wondering if you’ll be turfed out of bed and sent home at virtually no notice. Being on tenterhooks is unlikely to help you get better: the worry could make you much worse. To maintain your sanity one of your aims must be to reduce uncertainty. So ...

Second, find out who is taking decisions about you. While you still have your bed, ask the question: ‘Who takes decisions about when and where I go next?’ Take every opportunity to put some questions to that person.

Third, think about the exact wording of your questions. Here are some suggestions:

- What are the usual stages in recovery from my ailment, and how far am I along that road?
- How can I measure my progress, and what should be my next milestone?
- When and how will I know that I’m better?
- Which of the criteria for discharge in your list do I already meet?
- When will you want to move me out?

#### **5. Once you are deemed suitable for discharge ...**

Once you are deemed suitable for discharge, you move on to Stage 2 of the ‘discharge to assess’ model. This says that, wherever you are headed, you must be transferred to an allocated discharge area or lounge in the hospital as soon as possible: within an hour if you are on pathway 0; on the same day if you are on another pathway.

'On decision of discharge', as the rulebook puts it, you and your family or carer, and any formal supported housing workers, should be informed and receive one of two leaflets (shown in the rulebook's Annex B). This will tell you: 'You are being discharged from hospital as your health team have agreed that you are now able to return home / able to continue your recovery in another care setting, outside of hospital.'

Once you get the leaflet, and if it's the one telling you that you are going straight home with no support (pathway 0), the rulebook specifies that ward staff should be arranging discharge. So ask them, if they don't immediately volunteer the information, what arrangements are being made, and whether your family have been consulted and have approved (not just been informed).

If you will require reablement, rehabilitation and/or some care followed by further assessment after recovery, a case manager will be allocated to you and a decision made about which pathway will be used. So you need to ask, if you aren't immediately told: 'Who is my case manager?', and ask that person what is going on.

Case managers are told that they will be responsible, in liaison with ward staff, for ensuring (for everyone leaving hospital on pathways 1-3) that:

- Individuals and their families are fully informed of the next steps.
- Arrangements to transport people home from hospital are confirmed. This should be via family or carers, voluntary sector, or taxi, and only as a last resort, non-emergency patient transport (NEPTS).
- 'Settle in' support is provided where needed.
- COVID-19 test results are included in documentation that accompanies the person on discharge (where a test has taken place).

If you find yourself on pathway 2 or 3, ask your case manager: 'What options for me are you considering? If the answer is that you have no option and your destination is not your own home but has already been decided – 'We have managed to get you a bed at X' – ask how that decision was arrived at: 'What alternatives did you consider? What did you see as the pros and cons of each?' If you really don't want to go to X, for whatever reason, you might also like to ask if arrangements can be made for you to move on to Y when a bed there becomes available.

## **6. What happens to you in hospital: hospital-acquired deconditioning**

When you go into hospital for treatment you will almost always get better in some ways but worse in others.

You will get better in the sense that the injury or ailment that caused you to be admitted to hospital is put right, but you may well get worse in the sense that you become physically weaker (i.e. you lose muscle strength) and mentally frustrated and distressed. The technical term for this is 'hospital-acquired (or associated) deconditioning'. It comes about through staying in bed for extended periods and undertaking little or no physical exercise. As Jane Cummings says:

We know that for every 10 days of bed-rest in hospital, the equivalent of 10 years of muscle ageing occurs in people over 80-years old, and building this muscle strength back up takes twice as long as it does to deteriorate. One week of bedrest equates to [10% loss in strength](#), and for an older person who is at threshold strength for climbing the stairs at home, getting out of bed or even standing up from the toilet, a 10% loss of strength may make the difference between dependence and independence.[\[6\]](#)

Your mental health inevitably suffers too. You can't plan ahead, you have no control over the pattern of your day, and having things done for you weakens your confidence in doing them for yourself.

Not only that. If you have had family or other people living at home with you, and they see you going downhill, they get to doubt their own ability to give you that bit of care you need. And then it's easy for them to be persuaded that a care home is the best place for you.

In over-stretched community hospitals, the pressure on staff means that physiotherapists have to divide their time between you and many other patients; nurses find managing wards is easier if patients can be kept to their beds rather than allowed to wander about; and staff in general find it less time-consuming to care for patients rather than encourage them to care for themselves.

#### **7. There is no conspiracy to keep you in, but ...**

On the plus side, no-one in the hospital wants to keep you in unnecessarily. They would like to see you leave in a good state and happy with the care you've received. They would like to have your bed available for another patient. They certainly don't want you coming back later because you've had a turn for the worse. So they want to be sure your treatment is working as it should.

Hospitals are complex organizations. There is a management hierarchy, as well as doctors and nurses of various levels of seniority. There are other health professionals and people carrying out many ancillary and technical functions. And when it comes to patients leaving, especially older people living with frailty and living on their own, the hospital needs to assure itself that they will be able to cope, so more staff are involved in checking on this. Everyone is aware that if something goes wrong there is a buck that will stop somewhere, and if it leads to litigation the costs of legal fees can be very high.[\[7\]](#)

The result is that no-one is placing value on your time, so you are kept waiting: for decisions, for information, for attention when you need something. All of this is a sign of their failure to put your well-being first, possibly even to give thought to how you are feeling.

#### **8. How you need to be before you can leave: recovered, physically fit, mentally fit**

For you to get yourself out through the door, there are three things you need:

1. You need to have recovered, or be well on the way to recovery, from the accident or condition that landed you in hospital. If you broke a limb, it must be mended. A wound must be healed, or at least there must be a clear plan for its ongoing management after you're discharged. If you've been ill, you must be free of the symptoms.



2. You must be physically fit, sufficiently so that when you leave you are able to keep yourself clean, properly fed, properly exercised (with support if necessary). Bear in mind that without exercise physical decline can be very rapid: just two days in bed (see Jean's story in Appendix A) can severely reduce your ability to look after yourself unaided. As we see from the patient stories, hospital-based physiotherapists have in practice the power to stop you from being discharged other than into care of some kind.

3. You must be mentally fit. To resume normal life you must be capable of taking decisions and organizing your activities. Waking up in the morning day after day to find yourself stuck in a hospital bed, and subject to an institutional routine, is bound to destabilize you.

This will be especially so since other people will be telling you what to do, in a way that you may not have experienced since you were a child. Your circumstances may have changed very abruptly, especially if you've had an accident. You're likely to find yourself feeling very sad and tempted to give up, to become resigned to your fate. But to take the decisions necessary to make a successful escape you need to be in control of what's going on in your own head.

None of the available information about hospital-acquired deconditioning explicitly mentions the patient's mental health, and nor do the four patient stories in Appendix A. But we can see that in all four of those cases the patient had been abruptly plucked from familiar surroundings and was now being deprived of stimulus, of control over their own daily pattern of life, and of the opportunity to discover from those in positions of power what the future might hold for them. These deprivations cannot possibly have helped them to maintain a good level of mental health. What we see in those four stories is a process that, irrespective of their physical health, inherently disables people by inducing in them a state of frustration and despair.

If you're in that position, you need to resist!

What can you do?

The remainder of this guide has some suggestions.

### **9. Be aware of what's going on around you**

We can see from the patient stories how disorienting, discouraging and generally damaging it is not to know what's going on around you: what's being done to you and for you, where it's heading, and what stands in the way of your leaving.

Being aware of what's going on around you is the first rule of resisting. Practise being observant. Notice what's going on. What happens on the ward that you're in? What is the daily routine? How do the staff who are looking after you behave? Do they seem well-trained and used to working smoothly with one another? Or do they get flustered easily?

Notice who gives orders, and to whom? Can you tell at a glance who's senior, who's new, what the 'pecking order' is? What do you notice about the relationship between trainee doctors and experienced nurses? How are students treated: with kindness or with mockery? Are all patients treated in the same way or do you observe differences?

Just being aware of what's going on around you is a way of taking you out of yourself, away from brooding on how bad you're feeling, away from sinking into depression.

Ask to see – or at least be told – what records of your condition are being kept. After blood samples have been taken, ask what they showed. Watch the doctors and nurses and other staff, and make an effort to overhear their conversations. Do doctors consult nurses about how you have been since they last saw you? How is information about your condition passed on? When someone asks a question about you, do they get a straight answer or do you have a sense that people are being evasive?

### **10. Keep a diary**

Keeping a diary is a brilliant way of keeping tabs on what is going on for you and around you. You can jot down your observations of your surroundings, of course, and how you are feeling day by day. It is somewhere to record what you have done to keep up your physical fitness and mental fitness (see below). It is also particularly good for recording day by day what was done to you and for you in the course of your treatment, and what progress you have made.

A diary can be an old-fashioned notebook in which you note the events of the day and write down your observations and feelings. If you are technology-savvy, then use a smartphone or tablet to keep notes, or to send messages to yourself or to a friend or member of your family.

### **11. Exercise your body**

The patient stories in Appendix A demonstrate the huge importance of keeping up your physical fitness. So make the most of any physiotherapy that is offered. Ask to be shown any exercises that you can do on your own, and ask how to measure your progress. If you are keen to keep fit, and prepared to make the effort, any good physiotherapist will be enthusiastic about helping you (and you'll find you have a stronger claim on that precious resource, their time): your progress will be a credit to both of you.

### **12. Ask for help in keeping mentally fit**

Just as you wouldn't think twice before asking for help to keep physically fit, you shouldn't think twice before asking for help to keep mentally fit. Take advantage of any opportunities to keep your mind active. Some kind of counselling service should be available in an acute hospital: ask what's available to you. Is there a psychiatric liaison team, perhaps? A counsellor should be able (1) to suggest how to keep your mental agility up to scratch, if necessary, with games and other exercises; (2) to help you maintain your attention span when you watch news or current affairs programmes on TV, or read, or listen to music; and (3) most importantly, to help you with your state of mind.

You should be able to talk to a counsellor in confidence about the fears and anxieties that you have about being in hospital and what the future holds for you. A counsellor could also act as a communication channel, someone whom you can ask about decision-making processes within the hospital and who might be willing to pass messages on tactfully to doctors, nurses, physiotherapists and other members of staff whom they know.

### **13. Don't worry about being a nuisance**

Many people spend their lives not wanting to be a nuisance. 'I didn't want to bother the doctor' is often given as the reason for not going to the surgery earlier with a complaint that subsequently turns out to be serious. As a child, you may have learned that asking a lot of questions at school or home will get you labelled 'disruptive'.

If you definitely want to go home from a community hospital, and are encountering what seem to be bureaucratic obstacles, you will probably have to be really determined. Don't be put off. If you have close family, they may worry that you won't regain your former liveliness and will become (more) demanding: another reason why you should speak up for yourself.

You may never have done this before. Perhaps you know some argumentative people and don't like them very much, and don't want to become like them. Put such qualms aside!

### **14. Be aware of 'hospital strategies' for freeing up beds**

If the powers that be think there is nothing more that they can do for you – you are 'cured', or 'healed', unnecessarily taking up a bed, or whatever – they will want you out of your bed, to free it for an incoming patient. If you aren't able to move back into your own home, or able to afford a room in a private residential home, they will look for a place for you supported by local authority social services in a care home. Let's call the person doing this the 'discharge arranger'. (Official titles vary.)

If there is a shortage of beds or rooms, you may be offered just a single place, no choice of where to go. Now you have a dilemma. Do you accept what you are offered or hold out for something more suited to your preferences, such as somewhere close to where you previously lived?

Being placed in this situation is bound to cause you some anxiety. What can you do?

The first thing to do is to ask what options are available. Being able to make a choice will show you if there is somewhere else that you might prefer. It will also help you get clearer in your own mind what your criteria are for choosing a place. And it may open up the possibility of explaining what's in your mind to the discharge arranger and having a reasoned discussion with them.

If you aren't offered any option, be very wary. In particular, *do not sign anything!*

Signing a piece of paper will mean you are agreeing to something, and it may not be immediately apparent what it is that you're being asked to agree to. Say that you need to think about it. And hold on to the piece of paper, so you can show it to visitors.

If you have family or a close friend, the discharge arranger may bring them into the discussion. This will introduce further complications, of course. Family members may have their own views about what's best for you, which could be different from yours, and about whether your needs are likely to become more demanding, and what help they might be in a position to provide for you. So careful but frank negotiation will be called for here.

Bear in mind that the discharge arranger will have their own agenda. If they are under pressure to free up your bed, they may promise you that a place in a home that you don't feel comfortable with will be only temporary. But look at Jean's story (in Appendix A). She was held in a 'temporary' bed for more than three months, a period that ended only when she died. We have to ask: Did 'parking' her in this way simply allow staff to turn their attention to the pressing needs of other patients? Once she was out of sight did that mean she was out of mind?

### **15. Your rights ... and the reality**

According to the NHS Constitution: 'You have the right to receive care and treatment that is appropriate to you, meets your needs and reflects your preferences.'<sup>[8]</sup> The handbook on the Constitution adds that your need for care and treatment must be met (subject to certain provisos), while your preferences should be reflected where possible.<sup>[9]</sup>

It was the very clear preference of all the patients in the four stories in Appendix A that they should be encouraged and empowered to leave hospital and return home. In none of the cases did that come about. Even before coronavirus, the reality was that their constitutional rights weren't effective. Those rights existed in documents, but not in practice. You can't depend on them. As a patient, you can find yourself treated as if you are not entitled or competent to participate in decisions that affect you.

According to the organization NHS Improvement,

up to half the reasons why patients are not discharged earlier are under the direct control of the hospital itself and often relate to ineffective internal assessment processes, lack of decision-making and poor organisation of care management.<sup>[10]</sup>

These reasons may not necessarily disappear with the new rulebook in place.

So if you're to have the best chance of getting out at the earliest opportunity, it will help greatly if

- you know about these 'internal assessment processes' and can recognise them when you see them;
- you can get the doctors and managers to take decisions when you are ready, not just when it suits them;
- you notice how your care is being managed and speak up when it's not being managed in a way that reflects your preferences.

The following sections of this guide highlight aspects of decision making, management and other processes that you may be able to take advantage of.

### **16. Take advantage of NHS England's rules about when a patient is ready to go home**

In the days before coronavirus, NHS England, the body that supervises NHS hospitals, told them:

'A patient is ready to go home when all of the following three conditions are met:

1. A clinical decision has been made that the patient is ready for transfer home.

2. A multidisciplinary team decision has been made that the patient is ready for transfer home.

3. The patient is considered to be safe to discharge/transfer home.'[11]

So if you feel you are being kept in hospital when you ought to be released, you should ask if there is one of these conditions that has not yet been met. (Be prepared for the possibility that you'll be told that they don't apply any more.)

If it's condition 1, ask when the decision will be taken. 'Who will take the decision? Will it be taken during or following a ward round? When will it be taken?'

A doctor may tell you they need to say you are 'medically optimised' before they will be willing to discharge you, which sounds as though it is a decision which you can play no part in. But you can always ask some questions: 'How will you know when I am medically optimised? What will you be looking for? How close am I?'

If it's condition 2 that's holding up your discharge, ask who the members of the multidisciplinary team are. NHS England says they are expected to be people from all the relevant professional groups who have knowledge of you and the support you will need in your home setting. If you want members of your family or carers to contribute, you can ask for them to be involved too.

The role of the multidisciplinary team is to balance your requirement for health care, your desire to return home as soon as possible, the harm you might suffer if you stay longer in hospital, and the risks of being discharged home too early and having to be readmitted. Strictly speaking, these aren't clinical factors like the 'criteria to reside', but common sense – like NHS England pre-coronavirus – tells us they are relevant.

As you can see, what decision is arrived at will depend heavily on judgments. Hospital staff will judge your healthcare needs and the risks of early discharge, and may well want to be on the safe side, as they see it. They will also want to know how your basic requirements will be met: that's requirements for food, warmth, personal care, getting up in the morning and to bed in the evening, laundry, domestic cleaning and so on.

If you will need help with these, it would be very sensible to have this arranged before any meeting, so you can show people that you have thought about the arrangements you will have to make and have put them in place.

Finally, if it's condition 3, safety, that is still to be met, aim to ask in advance of any meeting what concerns staff might have about how you will fare at home, and do your best before any meeting to arrange to satisfy these too.

### **17. The last resort: to get more information, say you want to leave**

If, despite your best efforts, you are finding it difficult to get information from the hospital about what lies ahead, you have one more weapon in your locker.

The hospital should have a policy to support adult patients wanting to self-discharge against medical advice.[\[12\]](#) You can make use of this *not* to help you find yourself suddenly out on the street but to find out what is keeping you in.

It will be the policy of the hospital trust to support both you and the staff members involved. They will want to help you to understand why medical opinion advises continuing your hospital stay and to understand the possible implications of your decision to ignore medical advice.

The staff involved will be under instructions to try to discover from you what your reasons are for wanting to self-discharge against medical advice. So this is your opportunity to explain the frustrations that you are experiencing.

Describe the delays you have encountered, the promises that have not been fulfilled, the lack of information or the contradictory or erroneous diagnoses or other information you've been given. And say how these have left you feeling, and if you think your mental health has been suffering.

Your diary and any other notes that you have kept will be really useful in this situation.

Bear in mind that the consultant or other clinicians in your medical team will have a duty to establish the reasons why you wish to self-discharge and to address any issues that can be resolved at this point. This is your opportunity to give your message loud and clear. You should make sure, by the way, that what you are saying is being recorded.

Ideally you will be able to stay and complete your treatment, and that will happen smoothly and expeditiously. This is, I think, a reasonable expectation for you to have.

### **18. Getting discharged from an acute hospital to a community hospital**

If you are an elderly person who has suffered a fall and broken a limb, once the fracture has been set in an acute hospital and is on the mend you and the hospital will both want you moved to a properly equipped place where you can enjoy reablement and rehabilitation, continuing your recovery in a calmer environment and where there are staff – especially physiotherapists and occupational therapists – who can help you return to normal life. A community hospital should be just such a place.

Unfortunately, there have been many closures of community hospitals in recent years. In Cornwall this has had the result that many of those remaining are functioning with more than 90% of their beds occupied overnight. Some of them are themselves poor at moving patients on: a recent study concluded that around two-thirds of 'community beds' in Cornwall were occupied by patients who would be better suited elsewhere.[\[13\]](#) The main acute hospital has patients who are medically fit for discharge and ready to move on to a specialist reablement and rehabilitation facility but are unable to do so because there aren't the beds available.[\[14\]](#)

We can understand why even before the coronavirus pandemic the NHS has been so keen on getting patients back in their own homes as soon as possible, even though it means that to care for them physiotherapists have to spend a good deal of their precious time driving from one patient's home to the next with only as much equipment as they can transport.

What this means for you as a patient in an acute hospital seeking to move on is that you may need to have a clear strategy to get the reablement/rehabilitation service you need. Befriend the physiotherapists whom you meet, show that you appreciate the service they provide and are able to benefit from it. Ask for recommendations as to what community hospital would be the best for you to move on to.

And try to get a move to the community hospital nearest to your home. At West Cornwall Hospital, a branch of Cornwall's main acute hospital at Treliske, it has been observed that patients whose home is closer to the hospital tend to get discharged sooner than those whose home is further away. It seems likely that this happens because it's more difficult for family and neighbours living further away to visit and keep in touch. So if you are offered a place in a community hospital some distance from where you live, even if you're told it would only be temporary, you have a good reason to hold out for somewhere closer.

### **19. Getting discharged from a community hospital**

The current rulebook has a section (9.4) on discharge from community hospitals. Bear in mind that it says that from the day you're admitted you should have an expected date of discharge (EDD) and be fully involved with your discharge planning. So you should ask what your EDD is and what stage your discharge planning has got to. Is anything holding up the process?

As in acute hospitals, there should be a daily review of your plan. This is supposed to focus on three questions:

- Why not home?
- What needs to be different to make this possible at home?
- Why not today?

The purpose of the review is to explore why you require rehabilitation in a bedded setting and whether you can be supported at home. The starting point – 'the default assumption' – will be 'discharge home today'.

So if you think you can't be supported at home the onus is on you to have your reasons clear in your mind and to be able to spell them out.

If you feel or suspect that you need to stay on for a time to get physically fitter, with more reablement/rehabilitation in the community hospital, talk to the people who are currently providing it for you and get their opinion, in as much detail as possible.

If, however, you are keen to get home regardless you need to be clear what will be necessary for this to happen. Think about what you will need to have provided for you, or have help with. Imagine what it will be like when you are home, whether you will be on your own or with one or more members of your family/household. Here, to get you started, are some questions to ask everyone looking after you about continuing the help you should have already been getting:

- What will I need by way of continuing healthcare, from a geriatrician, doctor or nurse?

- Will I have to spend much of the day in bed when I get home? If so, how can I avoid home-acquired deconditioning?
- Reablement/rehabilitation: what services/equipment will I need to continue my recovery from my accident/illness, and will they be available?

## 20. Discharge into the community

Discharge is a journey with a destination as well as an origin. If your destination is to be your own home, you will be moving from the care of the community hospital to the care of the organization that provides community health services in your local area. The job of its staff is to 'work closely with other system partners to facilitate timely discharge of people, particularly for pathways 1, 2 and 3'. You need to know what this requires of them.

Section 6 of the rulebook says they should:

- Have an easily accessible single point of contact who will always accept assessments from staff in the hospital and source the care requested, in conjunction with local authorities. (Have you been told who this single point of contact is and whether they will be accessible to you?)
- Deliver enhanced occupational therapy and physiotherapy 7 days a week to reduce the length of time a person needs to remain in a hospital or care home rehabilitation bed. (Will this service be available to you once you're back at home? At a reduced level?)
- Monitor the effectiveness of reablement and rehabilitation. You should know how this will be done. You should be able to monitor the monitoring.
- Use multi-disciplinary teams on the day a person goes home from hospital, to assess and arrange packages of support. You should be consulted about the assessment and arrangements made.
- Ensure provision of equipment to support discharge. Ask occupational therapists and physiotherapists for advice about the equipment you should have.
- Ensure people on pathways 1-3 are tracked and followed up to assess for long term needs at the end of the period of recovery. If you are on one of those pathways be aware of how and by whom you are being tracked and assessed.
- Maintain a focus on supporting timely onward transition of care for persons from community beds, including reablement and rehabilitation packages in home settings. During the coronavirus pandemic certain procedural requirements are in force: you can read about them in a document called *Community Health Services Standard Operating Procedure*.[\[15\]](#)
- Support the local authority to ensure that quality of provision is adequate and safe and/or that alternative provision is commissioned. If you are unhappy with the adequacy and safety of whatever provision is made for you, you can raise the matter with your local councillor as well as the community health team.



## **21. Advice for family and friends**

First of all, please read through this guide and look for ways in which you can encourage a patient – your friend, let's say – to help himself or herself. Check that they are getting exercise and mental stimulus, and keeping a diary so they can write down their experiences and thoughts. Encourage them if they seem to be losing hope.

Bear in mind that even though your friend may look tired and depressed, that doesn't mean they are going irreversibly downhill and will be incapable of looking after themselves when they get out. Yes, be realistic, but also optimistic, and share your optimism with them. Visit as often as you can. Make plans for their departure.

Be your friend's ally. They may have questions about their treatment and prospects but be shy about asking them. So ask their questions for them. And don't let anyone drive a wedge between them and you. If you are asked to meet with anyone from the hospital or a social worker, say, you might get useful information from doing that, so it could be helpful, but don't get drawn into withholding information from your friend. That would put you in a very difficult position: you could find yourself becoming a kind of conspirator against them. Your friend must be able to trust you. If they can't trust you, who can they trust?

And remember that, as mentioned above, if an attempt is being made to persuade your friend to accept a moving-on bed somewhere inconvenient with no alternative offered, that is an indication that they simply want them out of their bed as soon as possible. If you support your friend in staying put until a better offer is made, staff may try to label you uncooperative and make you feel guilty. If your friend is given no option and no reasons, my advice to you both is: Stick to your guns!

## **22. Good luck!**

I wish you every success.

And I would be very interested to hear about your experiences. You can email me, Peter Levin, at [spr4cornwallguides@gmail.com](mailto:spr4cornwallguides@gmail.com). Messages received will be treated in strict confidence: no details enabling identification of yourself or any hospital will be published without your consent.

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## **Appendix A: Trapped in hospital: four patient stories**

Here are the stories of four patients. The first two are from a report by Newton Europe.[\[16\]](#)

### ***Mike, aged 89***

Mike was enjoying an early evening at home when he tripped over the edge of a rug and hit his head on the side of a cupboard. He remained conscious and was able to get to the phone to call 999. He was seen swiftly in A&E and was found to have no serious injuries, just some bruising.

The medical team decided to admit Mike overnight for observation, as a precaution, simply to be sure he was safe to go home. A day or two passed, during which time some tests were carried out. They all confirmed that there had been no serious or lasting damage and no underlying cause for the fall. He had simply tripped.

10 days later, Mike was still in his hospital bed. By this time he had lost a good deal of mobility, so an assessment by the physiotherapy team was arranged. The physiotherapists felt that Mike really needed assessment by the occupational therapists, and also by the social work team. All of these assessments took further time to arrange, and the days turned into weeks.

Based on the assessments, a recommendation was made for 24-hour residential care and that is where Mike was placed.

The occupational therapist (OT) who conducted Mike's assessment felt very strongly that had the physiotherapists, the OTs and the social care team all worked together as a single unit from the outset, this scenario might have been avoided. They could have worked in parallel rather than in series, thereby dramatically reducing the time it all took.

[The] opinion of the OT and the other teams involved was that, had they worked more effectively together, Mike could have gone home, with reablement support for his mobility issues.

\* \* \*

### ***Jane, aged 85***

Whilst cleaning her kitchen, Jane, who has had insulin-dependent diabetes for 59 years, slipped on the wet floor and fell. Jane was enjoying living independently with the support of a care package to help monitor and control her diabetes. She was seen in A&E and admitted for observation and monitoring of her diabetic control.

10 days later, Jane was declared medically fit. She was keen to go home.

There was then a series of delays with discharge, as a result of some internal communication processes not working as well as they should. Three weeks following her fall, Jane developed a severe hospital-acquired infection. Two months after admission to hospital, Jane was discharged – to a residential home.

Had Jane's discharge been managed more effectively and rapidly, she would have been less likely to suffer a hospital-acquired infection and far more likely to have been discharged to her own home and independent life – as she had wanted.

\* \* \*

### ***Jean, aged 90***

Another example of decline, this time in a community setting, is provided by the Embrace Care project in Cornwall:[\[13\]](#)

Day 0: Jean, an elderly woman with a history of falls, has a fall at home. After a very short stay in the acute hospital, she is discharged to a community hospital.

Day 1: At this point Jean is able to use the commode, is washing herself (with some support to reach her feet), cleaning her teeth, brushing her hair, and is moving around. She says she wants to return home when she is discharged from hospital. A search begins for support at home to enable her to do this.

Day 60: After many attempts to source a support package in the community have failed, Jean is told she will have to be moved into an intermediate care setting while a long term support package is found. She spends the following two days in bed.

Day 62: Jean starts to require full support to wash herself.

Day 74: A support package has been found to allow Jean to return home. However, her needs have increased and her physiotherapist suggests that the support package is now not sufficient, and it is refused.

Day 78: A checklist is completed and Jean again expresses her desire to return home.

Day 89: Jean is moved into a temporary bed in a care home.

Day 185: Still in the temporary bed in the care home, Jean dies.

\* \* \*

### ***Ann, age unknown***

The fourth patient story is an anonymized account of two visits a week apart in July 2019 to an elderly woman patient in the Royal Cornwall Hospital at Treliske, near Truro. The visitor was from Healthwatch Cornwall.[\[17\]](#) On the first visit the patient was engaging and engaged:

[Ann says] 'I have good and bad days. It feels like I've been in hospital a long time – too long. ... I have no idea when I'm leaving. The doctors haven't spoken to me about leaving here yet. I'm worried about money. It's not always possible to get what you want. I'm from a large family and wish I could be with them now. But I'm quite happy here on the ward. The food is good and I'm well looked after.'

[The visitor says] 'We visited Ann again seven days later. It was like visiting a different patient. Last week she was engaging and although [she] clearly had a level of cognitive impairment, she had a degree of understanding and seemed happy and talkative. Today she seemed unhappy and distressed and kept repeating that she wanted to go home.'

\* \* \*

These four cases all date from the pre-coronavirus era. As we have seen, acute hospitals are now keen to see you leave as soon as possible. But if the result is that, like Jean, you are moved to a community hospital, you may have much the same experience as Mike, Jane and Ann with time-consuming administrative procedures but in a community setting instead.

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## Appendix B: Links to web sources (last accessed 22/09/2020)

- [1] <https://improvement.nhs.uk/resources/acute-frailty/>
- [2] <https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2018/11/Monthly-Delayed-Transfers-of-Care-Situation-Report-Principles-Definitions-and-Guidance.pdf>
- [3] [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/911541/COVID-19\\_hospital\\_discharge\\_service\\_requirements\\_2.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/911541/COVID-19_hospital_discharge_service_requirements_2.pdf)
- [4] [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/912199/Hospital\\_Discharge\\_Policy\\_1.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/912199/Hospital_Discharge_Policy_1.pdf)
- [5] <https://www.nhsconfed.org/acronym-buster>
- [6] <https://www.england.nhs.uk/blog/jane-cummings-32/>
- [7] <https://resolution.nhs.uk/2019/07/11/clinical-negligence-numbers-steady-but-rising-costs-remain-a-concern/>
- [8] <https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england>
- [9] <https://www.gov.uk/government/publications/supplements-to-the-nhs-constitution-for-england/the-handbook-to-the-nhs-constitution-for-england>
- [10] <https://improvement.nhs.uk/resources/guide-reducing-long-hospital-stays/>
- [11] <https://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2018/11/Monthly-Delayed-Transfers-of-Care-Situation-Report-Principles-Definitions-and-Guidance.pdf>
- [12] <https://spr4cornwall.net/wp-content/uploads/RCHT-supporting-adult-patients-wanting-to-self-discharge-against-medical-advice.pdf>
- [13] <https://spr4cornwall.net/wp-content/uploads/Embrace-Care-Diagnostic-Review-abridged.pdf>
- [14] <https://www.england.nhs.uk/statistics/statistical-work-areas/bed-availability-and-occupancy/bed-data-overnight/>
- [15] <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/04/C0198-community-health-services-sop.pdf>
- [16] [https://newton-cdn.ams3.cdn.digitaloceanspaces.com/pdfs/hybrid/NEW0164\\_DTOC\\_Brochure\\_Online\\_Spreads\\_1.0\\_1.pdf](https://newton-cdn.ams3.cdn.digitaloceanspaces.com/pdfs/hybrid/NEW0164_DTOC_Brochure_Online_Spreads_1.0_1.pdf)
- [17] <https://www.healthwatchcornwall.co.uk/sites/healthwatchcornwall.co.uk/files/20190809%20HC%20People's%20Experiences%20of%20Delayed%20Transfers%20of%20Care%20Final.pdf>