

THE CF MANIFESTO

SCOTLAND

I deserve
fair care

CF CYSTIC
FIBROSIS
TRUST



This unit is for medical treatment by prescription and under the direction of a qualified health professional.

WARNING: DO NOT COVER AIR COOLING VENTS WHEN THE PORTA-NEB IS IN USE.

After each treatment, rinse your drug container in warm, soapy water and leave to dry. Reusable drug containers must be boiled once a week, in water with a little washing up liquid (5-10 minutes).

For more information read the instruction booklet.

Customer Services ☎ 0800 130 0845

The Scottish CF Manifesto

People with Cystic Fibrosis (CF) must have safe, fair care wherever they live in Scotland.

These four points are what the Cystic Fibrosis Trust and the CF community expect from whoever forms the next Scottish Government.

1. All people with CF to be cared for by an adequately resourced, specialist multidisciplinary team.
2. All people with CF to have equality of care across Scotland.
3. All people with CF to have clean inpatient and outpatient facilities, safe from the risk of cross-infection.
4. All people with CF, and indeed everyone on the transplant list, to have the best possible chance of receiving a life-saving transplant.

1. All people with CF to be cared for by an adequately resourced, specialist multidisciplinary team.

The situation

There is a worrying trend in paediatric care for the specialist posts, such as CF Nurse Specialists, to be asked to perform other non-CF duties. This takes them away from their care for children with Cystic Fibrosis and can be used as an excuse by hospital management that the posts should become general positions and not provide the specialist care that is needed by people with Cystic Fibrosis.

What the CF Trust is doing

The CF Trust calls on whoever forms the next Government to ensure that funds for specialist posts are ring-fenced in the same way that they are in adult care. This would solve the problem of health boards dictating the provision of specialist nursing care for children with Cystic Fibrosis.

What the next Scottish Government needs to do

The next Scottish Government needs to continue to support the National CF Managed Clinical Network which aims to strengthen and develop specialist services for children with Cystic Fibrosis in Scotland.

2. All people with CF to have equality of care across Scotland.

The situation

The best care for people with CF is by a specialist multidisciplinary team at a Specialist CF Centre or via a network arrangement with local providers; a fact recognised in Scotland, across the UK, and throughout Europe and North America. If a person with CF has the appropriate level of care from birth, they will lead a longer life. The specialist team comprises specialist CF consultants, specialist CF nurses, specialist CF dieticians, specialist CF physiotherapists, social workers, psychologists and other health professionals.

The resourcing of this care is inconsistent across Scotland, especially in psychosocial matters with little or no direct support from psychologists and social workers attached to CF teams. As people with CF are living longer, there is a need to expand adult services to maintain an appropriate level of care and support.

What the CF Trust is doing

The CF Trust has carried out a national psychosocial survey to highlight this gap in service and is currently analysing the results of the responses which will bring to the fore the pressing need for the engagement of support staff, not only across Scotland but the UK as a whole.

What the next Scottish Government needs to do

The next Scottish Government needs to ensure that the gap in health and social care is bridged to alleviate pressures on clinical staff and ensure that CF patients requiring additional support can access this via their multidisciplinary team instead of hospital wait lists.

3. All people with CF to have clean inpatient and outpatient facilities, safe from the risk of cross-infection.

The situation

People with CF can carry different organisms (bugs) that are harmful to those with CF and which can be passed on to others with Cystic Fibrosis. For this reason, it is imperative that hospital facilities, both inpatient and outpatient, have sufficient space and clinic time to prevent patients from mixing. They should also be well supplied with gels to minimise the risk of infections.

There is a wide variation in the facilities available for the care of those with Cystic Fibrosis. Whilst some hospitals provide a clean and safe environment, others, due to a lack of room and resources, struggle to maintain an acceptable standard. Currently, some outpatient facilities are not suitable for CF clinics with too great a chance of families mixing and as inpatients, people with CF may have to share a ward instead of having a room or cubicle.

What the CF Trust is doing

Through peer review, the CF Trust identifies where there are concerns about potential cross-infection and notifies the CF teams and the hospital management. The CF Trust also produces consensus guidelines (written by teams of clinical experts) on the standards of care

and management of these organisms, which indicate the consensus view of cross-infection procedures. These guidelines are accepted nationally and internationally.

What the next Scottish Government needs to do

The next Scottish Government needs to continue with improvements to the cleanliness of hospitals to help prevent infections for everyone. Steps must also be taken to ensure that money marked for spending on frontline care reaches the patients rather than being absorbed into the overheads and costs of hospitals.

4. All people with CF, and indeed everyone on the transplant list, to have the best possible chance of receiving a life-saving transplant.

The situation

Many of those with CF on the transplant list die waiting for their life-saving lung transplant. A third of those on the lung transplant waiting list have CF, but only a fifth of all lung transplants done in the UK are for CF patients. Although we encourage everyone to sign up to the Organ Donor Register to donate their organs when they die, donor numbers are only one part of the problem. Under the current system the donation process is not always well-managed meaning not enough potential donors end up donating organs and not enough organs are used per donor.

What the CF Trust is doing

The CF Trust is funding a research project in Newcastle aimed at improving the number of donor lungs that are viable for transplantation. As the transplant network works across the UK, this will have potential benefit for those in Scotland. This work takes currently unusable lungs and puts them through a procedure outside the body to remove inflammation and help repair them. Several transplants have so far taken place across the UK using these treated lungs.

What the next Scottish Government needs to do

The next Scottish Government must continue to encourage people to sign up to the organ donor register, but this on its own is not enough. The Scottish Government must also improve the care of donors following brain death in intensive care units to ensure that maximum benefit is gained from this ultimate act of generosity rather than donated organs going to waste. They must also invest in trained professionals to communicate with bereaved families during the difficult time to ensure that potential donors are not missed.