

LIVING LONGER, LIVING BETTER: Our vision for 2016



Cystic Fibrosis Trust registered as a charity in England and Wales (1079049) and in Scotland (SC040196)

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INTRODUCTION

From Matthew Reed, Chief Executive

The Cystic Fibrosis Trust believes that everyone living with CF deserves the highest level of care and real hope for the future.

Over the last decade significant progress has been made in a number of areas to fight CF and the median predicted survival in the UK has increased to reflect this. However despite the opportunities there are still substantial challenges to be urgently addressed to make future hope a reality.

Living Longer, Living Better: Our vision for 2016 defines our ambition and focus of the next four years. The strategy defines the Trust's direction and focus across a number of areas with the overarching goal of ensuring that life affected by CF is not life limited by CF.

In order to reach that goal, the Cystic Fibrosis Trust will focus its work over the next four years on four key areas:

- Increasing length of life for those with CF
- Improving quality of life for those with CF and their families
- Increasing capacity of CF research and clinical care
- Expanding awareness of CF and its impact on individuals and families

By concentrating on these areas, the Cystic Fibrosis Trust, the only UK-wide CF – specific charity, will become an organisation which makes a positive impact, not one that simply focuses on output. Living Longer, Living Better will be underpinned by an ambitious and urgent research programme, transformational clinical care agenda, and stretching fundraising targets to facilitate it. This is an agenda of partnership with clinicians and other health care professionals, researchers, industry, other charities, the Department of Health, and other actors.

During the development of this strategy, the Cystic Fibrosis Trust has worked with the CF community – with adults with CF and the parents of children with CF – as well as clinicians, and research professionals. While this is the Cystic Fibrosis Trust's strategy, it is driven and inspired by them.

Matthew Reed.





It is hard to believe that the first UK diagnosis of Cystic Fibrosis (CF) occurred less than 100 years ago, in 1943. At that time, and indeed for a large part of the twentieth century, CF was a childhood disease, with those who made it to school age branded ‘survivors’.

IN THE MORE THAN 70 YEARS since that first diagnosis, improvements in the understanding, management and treatment of CF have taken it from a disease of infancy to a long-term condition. The strides already made have increased the predicted survival in the UK to 41 years¹, but the CF community is determined to improve this position yet further.

The establishment of the Trust was, for many, a beacon of hope, but it had to be more than that. Over its first half-century, the Cystic Fibrosis Trust has actively supported research, both in a clinical and a laboratory setting, paving the way for the treatments which are available to people with CF today. In every decade that the Cystic Fibrosis Trust has existed, it has improved the understanding of CF by clinicians and those affected by the condition.

As a result of the Cystic Fibrosis Trust’s advocacy, the sweat test used to diagnose Cystic Fibrosis, discovered in the US in 1959, was adopted by many UK doctors by the late 1960s. However, better identification of the disease was useless without greater understanding or treatment of it. The Trust, then as now, acted as a conduit for international thinking on CF, from the greater use of physiotherapy and more effective use of antibiotics to improved nutritional therapy and substantial support for specialist CF care. It was this work that grew the Cystic Fibrosis Trust’s reputation and international standing.

The Trust does not exist merely to act as a channel for the ideas of others, however. Thanks to funding, support and advocacy, the Cystic Fibrosis Trust has helped to create generations of CF professionals, from physiotherapists to nurses, consultants to geneticists, leaders in their field not only in the UK but across the world. This work, and the dogged determination of the Trust’s supporters, has ensured that predicted median survival in the UK is the highest in Europe and higher than that of the USA².

“Children with CF born today can look forward to a life expectancy the Trust’s founding fathers would have found remarkable.”



The Trust’s work to introduce mandatory newborn screening for CF, in place across the UK since 2007, has ensured babies benefit from early intervention. As a result, children with CF born today can look forward to a life expectancy the Trust’s founding fathers would have found remarkable.

The investment in clinicians and the ground-breaking gene therapy programme have put the Cystic Fibrosis Trust at the vanguard of better treatment and understanding of CF in its first half century. Its ambition is undimmed as it enters its second.

¹ Source, UK CF Registry

² Source, UK CF Registry 2010 Annual Report

A VISION FOR THE FUTURE

In 1964, the year that the Cystic Fibrosis Trust was founded, a child with CF had just a 20 per cent chance of reaching school age, while reaching their teens was something approaching miraculous. Nearly half a century on, the prognosis for those with CF is much improved, thanks in no small part to the work carried out by the Cystic Fibrosis Trust and its supporters.



What can and must be achieved



THERE IS STILL MUCH TO DO, however. Improvements in treatments and better management of CF care have significantly increased the life expectancy of a person with CF, but this in itself has presented new, unforeseen challenges. With more people with CF living longer, the pressure on adult clinical services has greatly increased and further CF-related issues, such as diabetes and osteoporosis, are becoming more prevalent.

It is clear that, for a condition as complex as CF, there is no silver bullet, no one solution to its treatment and

management. Greater investment into the training and development of clinical and research teams is required to meet the new challenges posed by an ageing – and growing – CF population, as well as the ongoing needs of children and young people with the condition. And, of course, the search will continue for a cure.

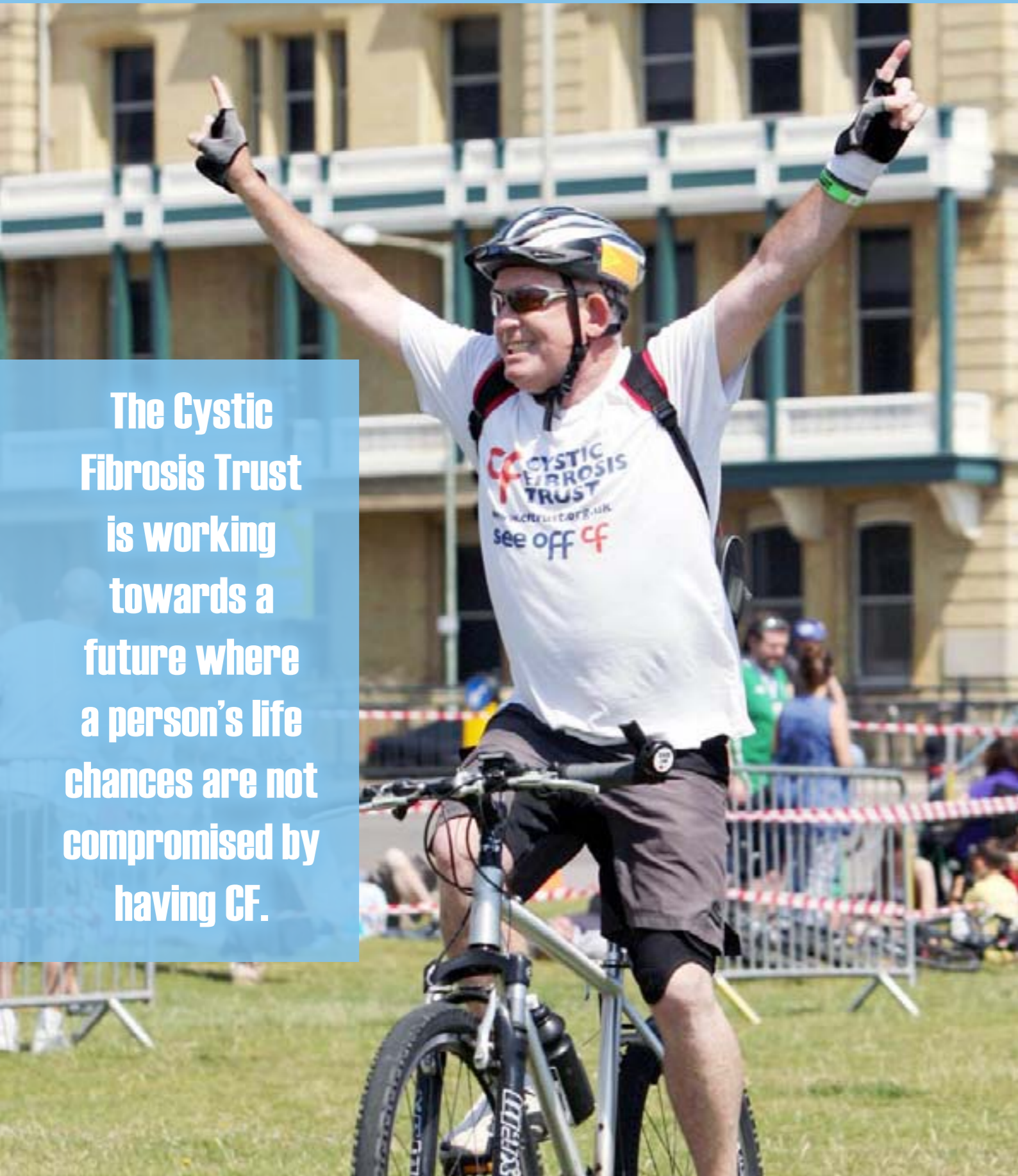
Living longer is not the only measure of success, though. The Cystic Fibrosis Trust is working towards a future where a person's life chances and aspirations are not compromised by having CF.

That means ensuring quality, as well as length, of life, opening doors to education, adventure, employment and family life. Greater awareness of the condition and its impact, both within and beyond the CF community, is vital to ensure the same opportunities are as available to those who have CF as those who do not.

There is no doubt that Cystic Fibrosis affects almost every aspect of a person's life, but it should neither define nor restrict them.

OUR VISION

The Cystic Fibrosis Trust is working towards a future where a person's life chances are not compromised by having CF.



OUR GOALS FOR 2016

When the Cystic Fibrosis Trust was founded in 1964, it aspired for improvement in the understanding and treatment of Cystic Fibrosis. As it enters its second half-century, that aspiration has not waned and our goals for 2016 are ambitious.

BY 2016, THE CYSTIC FIBROSIS TRUST WILL STRIVE TO:

- Increase the predicted median survival for people living with CF in Great Britain & Northern Ireland, working with its partners and holding decision-makers and care providers to account;
- Improve the quality of life for people living with Cystic Fibrosis, reducing the burden of CF and ensuring they are able to live a life unlimited by the condition;
- Develop the next generation of clinicians and researchers working in CF, ensuring longevity and growth in care and research provision;
- Advance the understanding and awareness of CF, both within the CF community and across society.



LIVING LONGER

In the UK, the average life expectancy is 80 years old³. Despite advances in the management and treatment of Cystic Fibrosis, the predicted median survival of someone with the condition is around half the national average. The Cystic Fibrosis Trust is determined to increase the predicted median survival for people living with CF in Great Britain & Northern Ireland by five years, from 41⁴ to 45. That is why, over the next four years, the Cystic Fibrosis Trust will identify and fund key areas of research designed to have the highest impact as part of the international fight against CF.

“ The Cystic Fibrosis Trust will identify and fund key areas of research designed to have the highest impact as part of the fight against CF. ”

THE CYSTIC FIBROSIS TRUST WILL SUPPORT EFFORTS TO REDUCE THE ONSET OF LUNG DAMAGE IN YOUNG CHILDREN.

Thanks to the concerted efforts of the Cystic Fibrosis Trust, newborn screening was rolled out across the whole of the UK in 2007. Many babies born with CF may appear to be healthy, but research suggests that lung damage may occur prenatally. The Cystic Fibrosis Trust will continue to drive and fund research both to develop early intervention and to track the impact of this work.

However, there continues to be variation in the level and quality of ongoing treatment provided, which can have a detrimental effect on a child's life chances. The Cystic Fibrosis Trust will work with the relevant NHS commissioning bodies and clinicians, both nationally and regionally, to ensure that early interventions are consistent and delivered in accordance with the prevailing Standards of Care so that all children with CF remain free of lung damage.

³ Source, World Bank (2009)

⁴ Predicted median survival in 2010 (Source: UK CF Registry)



THE CYSTIC FIBROSIS TRUST WILL SUPPORT EFFORTS TO ENSURE THAT YOUNG ADULTS WITH CF MAINTAIN THE HIGHEST POSSIBLE LUNG FUNCTION FOLLOWING TRANSITION TO ADULT SERVICES.

Giving children the right start is vital, but we also have to ensure that treatment and care consistent with the prevailing Standards of Care continues through every life stage. Transition from paediatric care to adult services can be difficult, particularly if this means moving from one specialist centre to another. Through its Peer Review programme and Registry, the Cystic Fibrosis Trust will research transition best practice using this work to develop transition standards with the NHS and relevant commissioning bodies across the four nations and will measure services against those standards.

The Cystic Fibrosis Trust will also work with others to establish best practice in adherence to treatments among teenagers to give young people the best possible chance of a long adult life. This will allow young people to move seamlessly between paediatric and adult services and ensure that progress made in early years is not lost. In addition, the Cystic Fibrosis Trust will support further social and clinical research to understand the barriers to successful transition from parent-managed care to self-management of care and, working with clinicians, parents and young people, how to overcome them.

THE CYSTIC FIBROSIS TRUST WILL SUPPORT EFFORTS TO ENSURE THAT ALL THOSE WITH CF WHO ARE ASSESSED AS SUITABLE FOR A LUNG TRANSPLANT RECEIVE ONE.

While new treatments and better management of care are helping people with Cystic Fibrosis live longer, many will reach a point at which receiving a lung transplant is their only option to prolong life significantly. Despite this, nearly half of all people with CF on the waiting list will die before they receive a lung transplant. The Cystic Fibrosis Trust will develop a dedicated programme of work to overcome this, working with NHS Blood & Transplant and other organisations to develop a national standard for transplant services. In addition, the Cystic Fibrosis Trust will continue to fund research into ensuring more organs are available for transplant, such as the 'reconditioning' lungs programme. The Cystic Fibrosis Trust will also develop its print and online publications to help parents to discuss the issue of transplantation with their children and to enable people with CF to make informed decisions about their choices.

THE CYSTIC FIBROSIS TRUST WILL WORK WITH COMMISSIONERS TO ENSURE ALL ADULTS AND CHILDREN LIVING WITH CYSTIC FIBROSIS HAVE ACCESS TO DESIGNATED CF CARE.

Cystic Fibrosis is a complex, progressive multi-organ condition that requires lifelong specialist treatment. Despite National Standards of Care being in place since 1996, there are still too many adults and children with CF who are not receiving specialist CF care at designated specialist centres. The Cystic Fibrosis Trust will work with the relevant NHS commissioning bodies in the four nations to ensure everyone with CF is registered with a designated, properly resourced specialist CF service.

THE CYSTIC FIBROSIS TRUST WILL HAVE A BROAD RESEARCH PROGRAMME, BRINGING FORWARD MORE AND BETTER TREATMENTS FOR CF.

Since Cystic Fibrosis was first recognised in 1938, new treatments and new medicines have helped to improve the lives of those with CF, but many challenges still remain. The Cystic Fibrosis Trust will finance research aimed at having the highest impact on CF, expanding its research programme and working with its international partners to effect quick and decisive outcomes. Pending a successful outcome of the clinical trial, the Cystic Fibrosis Trust will continue to work with the Gene Therapy Consortium to embed its historical investment in Gene Therapy in any future commercially sustainable model.



“ The Cystic Fibrosis Trust will work with the NHS to develop transition standards. ”

LIVING BETTER



According to Socrates, “not life, but good life, is to be chiefly valued”. When Cystic Fibrosis was first recognised in the early part of the twentieth century, merely surviving was a measure of success. Now, rightly, people with CF have the same aspirations and goals as the rest of the population, with an emphasis not simply on life, but good life.

THE CYSTIC FIBROSIS TRUST WILL SUPPORT YOUNG PEOPLE IN FULL TIME EDUCATION, AS WELL AS EDUCATORS.

Having CF should not be a barrier to education. While young people with CF may have more to consider than their peer group, such as managing their medication, they are, for the most part, no different. The Cystic Fibrosis Trust will work with young people and educators to help them understand the potential impact of CF on school life and to dispel the myths often associated with the condition.

The Cystic Fibrosis Trust will work with teaching organisations and local government to ensure that pupils are supported in the management of their care. In addition, the Cystic Fibrosis Trust will work with higher and further education providers, including universities, to ensure that they are properly informed and equipped to support young people with CF.

THE CYSTIC FIBROSIS TRUST WILL SUPPORT AND IMPROVE ACCESSIBILITY TO, AND RIGHTS IN, EMPLOYMENT.

Perhaps in part because of the challenges they face on a day-to-day basis, people with Cystic Fibrosis are among the most driven and ambitious. Despite this, employers often overestimate the impact on their business of taking on people with CF. Similarly, for people with CF in employment, a lack of understanding of the condition can leave them feeling vulnerable and marginalised. The Cystic Fibrosis Trust will work with employers' organisations to improve understanding of CF and provide more and enhanced support to people with CF in employment.



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THE CYSTIC FIBROSIS TRUST WILL LOBBY GOVERNMENT AGENCIES TO ENSURE PEOPLE WITH CF GET THE RIGHT SUPPORT WITH RESPECT TO BENEFITS.

For some people with Cystic Fibrosis, working full-time, or even working at all, is not an option. State support in these cases is vital, yet often the lack of understanding of the impact of CF can leave them short of the support, both practical and financial, that they need. The Cystic Fibrosis Trust will work with the four national governments to improve understanding of CF and provide more and enhanced support to people with CF.

THE CYSTIC FIBROSIS TRUST WILL OFFER SUPPORT AND INFORMATION ON FERTILITY ISSUES FOR PEOPLE WITH CF.

For many, living a fulfilled life means having a family of their own. For those with Cystic Fibrosis, this can be fraught with difficulties, as CF can have a profound impact on fertility, for men and women. The Cystic Fibrosis Trust will provide support for would-be parents to explain the options available to them and information for parents of children with CF discussing puberty. In addition, the Cystic Fibrosis Trust will work with commissioners and clinicians to ensure that fertility services are available to people with CF and that there is co-operation between specialist CF and fertility services.



“ From receiving a new diagnosis as a parent to the challenges of living with CF as a teenager or adult, the impact on individuals and on family life can be great. ”



THE CYSTIC FIBROSIS TRUST WILL WORK WITH HEALTHCARE COMMISSIONERS TO ENSURE GOOD SOCIAL SUPPORT AND COUNSELLING IS BOTH AVAILABLE AND INCLUSIVE.

Cystic Fibrosis does not only affect the person with the condition: parents, carers, siblings and partners also live with the impact of CF. From receiving a new diagnosis as a parent to the challenges of living with CF as a teenager or adult, the impact on individuals and on family life can be great. In spite of this, outside support, whether simply having someone to share experience or more formal counselling, can be difficult to find.

Using its existing network of branches as a starting point, the Cystic Fibrosis Trust will develop local and regional networks for families and, using its own online Forum and other social media sites, virtual networks for teenagers and adults with CF.

In addition, the Cystic Fibrosis Trust will work with healthcare commissioners to ensure good social support, including dedicated social workers and psychological support and counselling, is available to both individuals and families living with CF, free at the point of use.

THE CYSTIC FIBROSIS TRUST WILL MEASURE IMPROVEMENTS IN QUALITY OF LIFE, ACROSS ALL ADULTS AND CHILDREN LIVING WITH CF

For each of us, quality of life is defined by something different. The same is true of the CF community: for some it may be the ability to have as 'normal' a life as possible, with all that embodies, while for others it may be just getting through the day. The Cystic Fibrosis Trust will work with clinicians and the CF community to develop a range of social metrics, such as those proposed by the Government's well-being index, in order to measure quality of life.



BECOMING STRONGER

Living longer and living better may be the aspirations of the Cystic Fibrosis Trust and its supporters, but the building blocks sit within the clinical and research communities, in the UK and beyond. The success in the management and treatment of CF has been achieved thanks to the determination and commitment of a small number of professionals, many of whom have been supported by the Cystic Fibrosis Trust. To make yet further strides, though, a new generation of clinicians and researchers needs to be found and nurtured.

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A career in CF is incredibly rewarding. Many of the current specialist clinicians and allied health professionals working in CF arrived there by chance and stayed by design.
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THE CYSTIC FIBROSIS TRUST WILL ENSURE CLINICIANS AND ALLIED HEALTHCARE PROFESSIONALS ARE ATTRACTED, SUPPORTED AND TRAINED TO WORK IN CF.

A career in CF is incredibly rewarding. Many of the current specialist clinicians and allied health professionals working in CF arrived there by chance and stayed by design. With a growing adult CF population, there is even greater demand on services, but with fewer professionals coming through to support them. The Cystic Fibrosis Trust will work with universities to attract those just starting out in their clinical career and with medical Royal Colleges, the Chartered Society of Physiotherapy, the British Thoracic Society and others to ensure that those across the clinical team, from doctors and nurses to physiotherapists and dietitians, receive the right support and training to sustain a career in CF services.

THE CYSTIC FIBROSIS TRUST WILL BE AN ADVOCATE AND CONDUIT FOR BEST PRACTICE IN SPECIALIST CF CARE.

There is undoubtedly excellent care and treatment of Cystic Fibrosis taking place across the UK. Often, however, it can be difficult to share this excellent practice and innovation with other teams. The Cystic Fibrosis Trust, through its Peer Review programme, will assess services against the National Standards of Care, using these assessments and the clinical outcomes for each service to collate information on best practice. It will use its existing networks to disseminate this information and encourage the implementation of best practice. The Cystic Fibrosis Trust will also develop its events and conferencing programme to share the latest developments and best practice in CF treatment and care.



THE CYSTIC FIBROSIS TRUST WILL CONDUCT AND COMMISSION SOCIAL RESEARCH TO DEVELOP UNDERSTANDING OF THE NON-MEDICAL IMPACT OF CF.

The impact of Cystic Fibrosis reaches beyond the medical. Its impact on social well-being, of the individual with CF, their family, friends and partners, can also take its toll. The Cystic Fibrosis Trust will conduct and commission research to develop better understanding of this impact, and its potential implications for quality and length of life.

THE CYSTIC FIBROSIS TRUST WILL ENHANCE CAPACITY FOR CLINICAL TRIALS IN CF IN THE UK.

Living with CF means living with a burdensome regime of drugs and treatments. With many people with CF taking almost 22,000 tablets a year, in addition to nebulised treatments which mean being attached to a machine for several hours, finding a way to reduce this burden and improve management is a clear priority. The Cystic Fibrosis Trust will work with its international partners and the pharmaceutical industry to ensure the pipeline for new medicines continues to grow.

The Cystic Fibrosis Trust will also utilise its Registry resource in order to monitor benefits and adverse reactions for new treatments. In addition, the Cystic Fibrosis Trust will facilitate and support a forum for UK members of the European CF Clinical Trials Network in order to develop the UK's position as a leader in treatment development.

“ The impact of Cystic Fibrosis reaches beyond the medical. Its impact on social well-being, of the individual with CF, their family, friends and partners, can also take its toll. ”

THE CYSTIC FIBROSIS TRUST WILL CHAMPION AND SUPPORT DEVELOPMENTS THAT REDUCE THE BURDEN OF CARE AND INCREASE COMPLIANCE.

Living with CF can be onerous. Every day people with CF have to take up to 60 tablets, undergo physiotherapy to keep their lungs clear and manage their diet to ensure they are getting the right nutrients, presenting a burden on them and, for children and young people with CF, their parents. The Cystic Fibrosis Trust will work with clinicians, researchers and the pharmaceutical industry to help reduce this burden, by encouraging the development of better, more effective treatments. The Cystic Fibrosis Trust will monitor the data available via the CF Registry to inform best practice. In addition, the Cystic Fibrosis Trust will develop more and better information and support for parents to facilitate better compliance at home, as well as in a clinical setting.

THE CYSTIC FIBROSIS TRUST WILL ENHANCE CAPACITY FOR MEDICAL RESEARCH ACROSS A RANGE OF AREAS.

Understanding a condition is key to its treatment, management and even cure. While the increasing survival rates of people with CF is welcomed, it adds new challenges, including fertility and osteoporosis, to the existing ones of lung disease, bowel problems and pancreatic damage. If we are to understand the fundamental defect of CFTR gene mutation and its impact on CF, more basic and applied research needs to be carried out and, as a consequence, more researchers are needed. The Cystic Fibrosis Trust will work with universities and research institutions to increase capacity for CF-specific studies. In addition, the Cystic Fibrosis Trust will work with other charities, professional associations and the pharmaceutical industry on jointly beneficial, non-CF specific research, such as the ongoing battle against resistant bacteria, and work with researchers to assist them in grant and scholarship applications.



SHOUTING LOUDER



Whether between patient and clinician, teacher and pupil or charity and the wider population, communication is key. Now, thanks to advances in technology and social media, people with Cystic Fibrosis who had previously been unable to meet face to face because of cross infection limitations, can talk and share their experiences, albeit virtually. For communication to work well, though, it needs to be regular and consistent.

THE CYSTIC FIBROSIS TRUST WILL BE THE TRUSTED SOURCE OF OBJECTIVE AND BALANCED INFORMATION ON ALL NEW DEVELOPMENTS WITHIN CF.

Receiving a diagnosis of Cystic Fibrosis can be daunting, and understanding the condition no less so. Finding the right information, written clearly and accurately, can be hard to find. The Cystic Fibrosis Trust will aspire to be a world authority in Cystic Fibrosis. To achieve this ambition, the Cystic Fibrosis Trust will continue to develop its trusted online and printed publications, targeted at people with CF and their families across all the major life stages. These will offer regular current, clear, balanced and objective information on new developments in CF, using the Cystic Fibrosis Trust's relationships with sister organisations across the world.

“ The Cystic Fibrosis Trust will continue to develop its trusted online and printed publications, targeted at people with CF and their families. ”



THE CYSTIC FIBROSIS TRUST WILL WORK WITH POLITICIANS AND POLICY-MAKERS ACROSS THE FOUR NATIONS TO INSTIL BETTER UNDERSTANDING OF CF AND ITS IMPACT, AND THE NEED FOR HIGH QUALITY, SUSTAINABLE SERVICES.

Despite decision-making in the National Health Service becoming increasingly devolved to national, regional and local levels, there is still an important role for the relevant Parliaments and Assemblies of the UK to play, particularly around the issues of welfare benefits and social support. The Cystic Fibrosis Trust will develop strong and sustainable relationships with politicians across the political spectrum and in each of the Parliaments and Assemblies to ensure that they understand the full impact of CF, on health and well-being, including its financial and social impact.

THE CYSTIC FIBROSIS TRUST WILL EMPOWER YOUNG PEOPLE WITH CF TO ENABLE THEM TO MAKE THE INFORMED CHOICES THEY NEED TO MAINTAIN GOOD HEALTH.

Most young people crave independence, but for those with CF, that independence comes with significant responsibilities over their own care. The Cystic Fibrosis Trust will work with paediatric specialist services to support young people through transition, providing more and better information. This work will pay particular attention to helping young people, and their parents, better understand their genotype and its implications for current and future treatments and the importance of compliance with their medication and physiotherapy regimes.

THE CYSTIC FIBROSIS TRUST WILL ENSURE THAT PEOPLE LIVING WITH CF AND THEIR FAMILIES RECEIVE EXCELLENT SUPPORT AND CARE BEFORE AND AFTER DEATH.

While everyone with Cystic Fibrosis aims to stay well for as long as possible, they understand that it is a progressive condition, currently without a cure. As the impact of their CF increases and their health worsens, it is vital that they and their families are well supported, not just by their clinical team, but pastorally too.

The Cystic Fibrosis Trust will work in partnership with other organisations to ensure that the wishes of people with CF and their families for end of life care are both supported and honoured. In addition, the Cystic Fibrosis Trust will develop its support services for bereaved families.

THE CYSTIC FIBROSIS TRUST WILL DEVELOP LEADING APPROACHES TO PATIENT AND WIDER COMMUNITY INVOLVEMENT INCLUDING THE USE OF TECHNOLOGY.

Cross infection controls can lead to isolation for people with CF, but the advent of social media has opened up a virtual world where they can meet and share experiences. The Cystic Fibrosis Trust will develop its social media output, working with people with CF to ensure their needs are met. In addition, we will work with specialist centres to allow free broadband access for all CF patients to minimise isolation.

THE CYSTIC FIBROSIS TRUST WILL SIGNIFICANTLY INCREASE PUBLIC UNDERSTANDING OF CF, MAKING IT EASIER FOR PEOPLE TO LIVE LIVES UNHINDERED BY CF.

Cystic Fibrosis impacts on every area of life, but it does not have to control every area. The more people that understand CF, the more integrated people with CF can be, in education, in employment and beyond. The Cystic Fibrosis Trust will work with the media, employers and educators to demystify the condition and to break down any barriers that currently exist.



“ We will develop strong relationships with politicians and policy makers. ”

OUR GOVERNANCE

PATRON: HRH Princess Alexandra GCVO KG

HONORARY PRESIDENT: Dr Jim Littlewood

CHIEF EXECUTIVE: Matthew Reed

TRUSTEES: Jenny Agutter
Giorgia Arnold
Sir Peter Cresswell
Katrina Dujardin
Professor Stuart Elborn
Allan Gormly (Chair)
Brian Henderson
Archie Norman
Ed Owen
Rupert Pearce Gould (Hon Treasurer)
Professor John Price
Martyn Rose
Peter Sharp