FINDING THE LIGHT TO BLOOM

Thriving Together

FESCA

World Scleroderma Day

Boehringer Ingelheim

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Finding the Light to Bloom

This book is dedicated to all those living with scleroderma.

A big thank you to 8 year old Coco, for the beautiful drawing of a sunflower.

It’s an honour to be writing this foreword – a chance to give people living with scleroderma a voice, to thank families and carers, and to show that we are all finding the light to bloomtogether. This is of great personal significance, as my sister had scleroderma. I witnessed not just her struggles, but her amazing bravery and determination to live a full life. I see this from so many in our community, as they push for better treatment and care.

Every day, I work with some of the 2.5 million people living with this rare, chronic auto immune disease – and I’m just as often confronted with people who have no idea what scleroderma is. One of the most arresting descriptions I’ve heard is that it feels like your body is turning to stone. This feeling is driven by excessive deposits of collagen which stiffen the skin, potentially affecting internal organs and causing debilitating complications within the immune and vascular systems. While treatments exist, there is currently no cure. That’s why individuals with scleroderma must be diagnosed as early as possible.

The Federation of European Scleroderma Associations (FESCA) exists to raise awareness of this chronic condition, advancing the policy agenda while connecting policymakers, healthcare professionals, industry, and of course people living with scleroderma themselves. Every year, we honour our community by celebrating World Scleroderma Day on June 29th. In 2023, we conducted a Europe-wide survey to find out more about the unmet needs of the patient community. With over 1,200 responses, we are grateful to those who allowed us to shine a light on their day-to-day challenges. In addition, we are proud to release “Find the Light to Bloom” – the story of one patient’s journey with scleroderma through dance. Dancing allows us to express emotions that can be difficult to communicate through words, and the art of movement set to music is a universal language. It became the perfect opportunity for us to depict the challenges that those with this condition face, every single day.

We are extremely grateful to all those involved in bringing the campaign to life: to Briana Stuart for beautifully expressing the journey of a scleroderma patient through dance. To Arnaud Beelen for his significant contribution in photographing and editing the video of the dance. To Leo Foulet for capturing the dance on film in such a captivating way. To Steven Brys for his involvement as a light designer, and to Michael Wall for allowing us to use his beautiful song in the video. To our sponsors, Boehringer Ingelheim, Horizon Therapeutics and Janssen. And to the Weber Shandwick team for all their support.

Together, we are seeking to remind people with scleroderma that they are not alone in the challenges they face. We are working together to unite the scleroderma community, connecting individuals with resources that will lessen the burden of this chronic illness. This project is a testament to those with scleroderma – and a celebration of the power of the human spirit.

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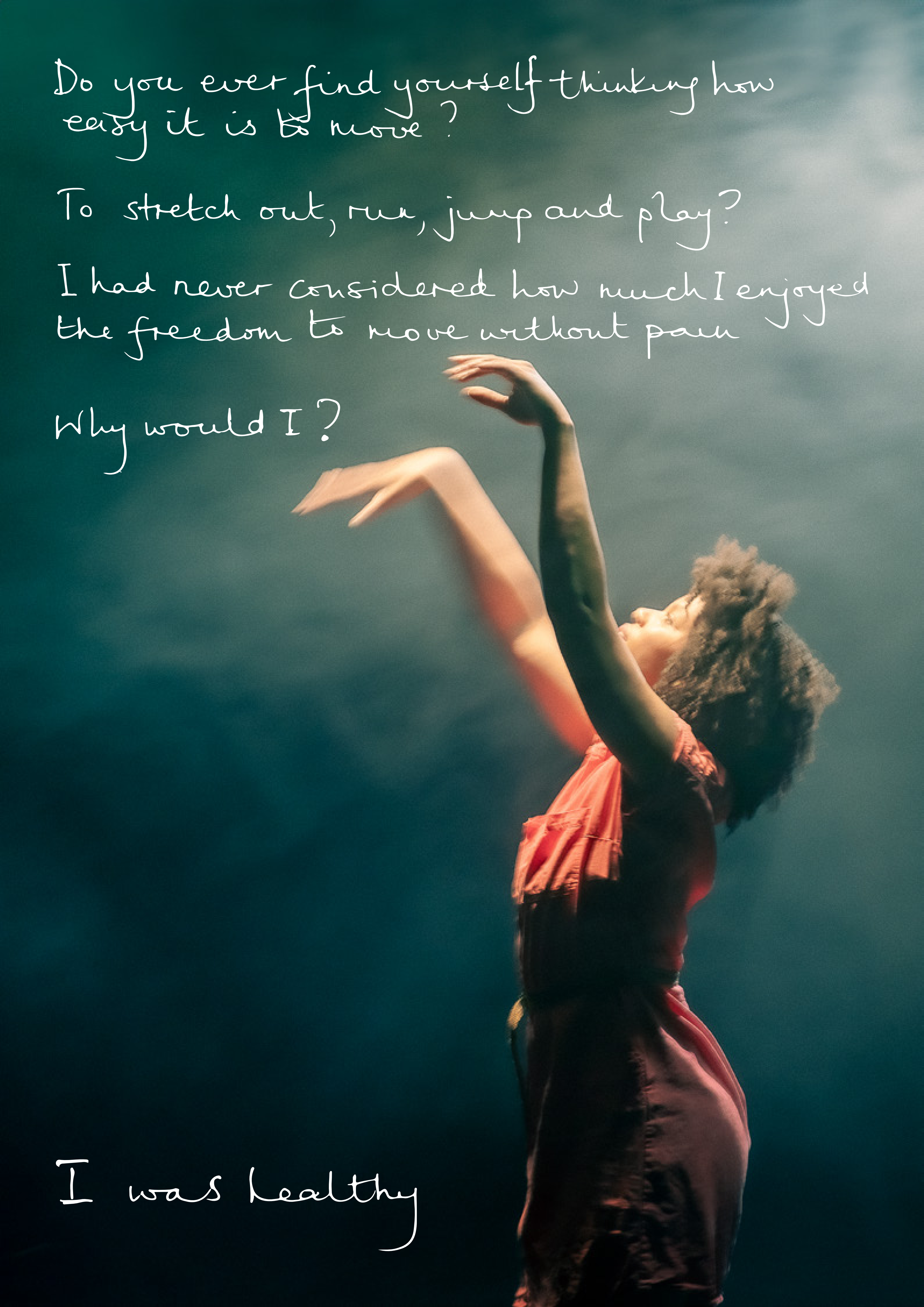
Sue Farrington
President, FESCA, Federation of European Scleroderma Associations



Do you ever find yourself thinking how easy it is to move?

To stretch out, run, jump and play?

I had never considered how much I enjoyed the freedom to move without pain

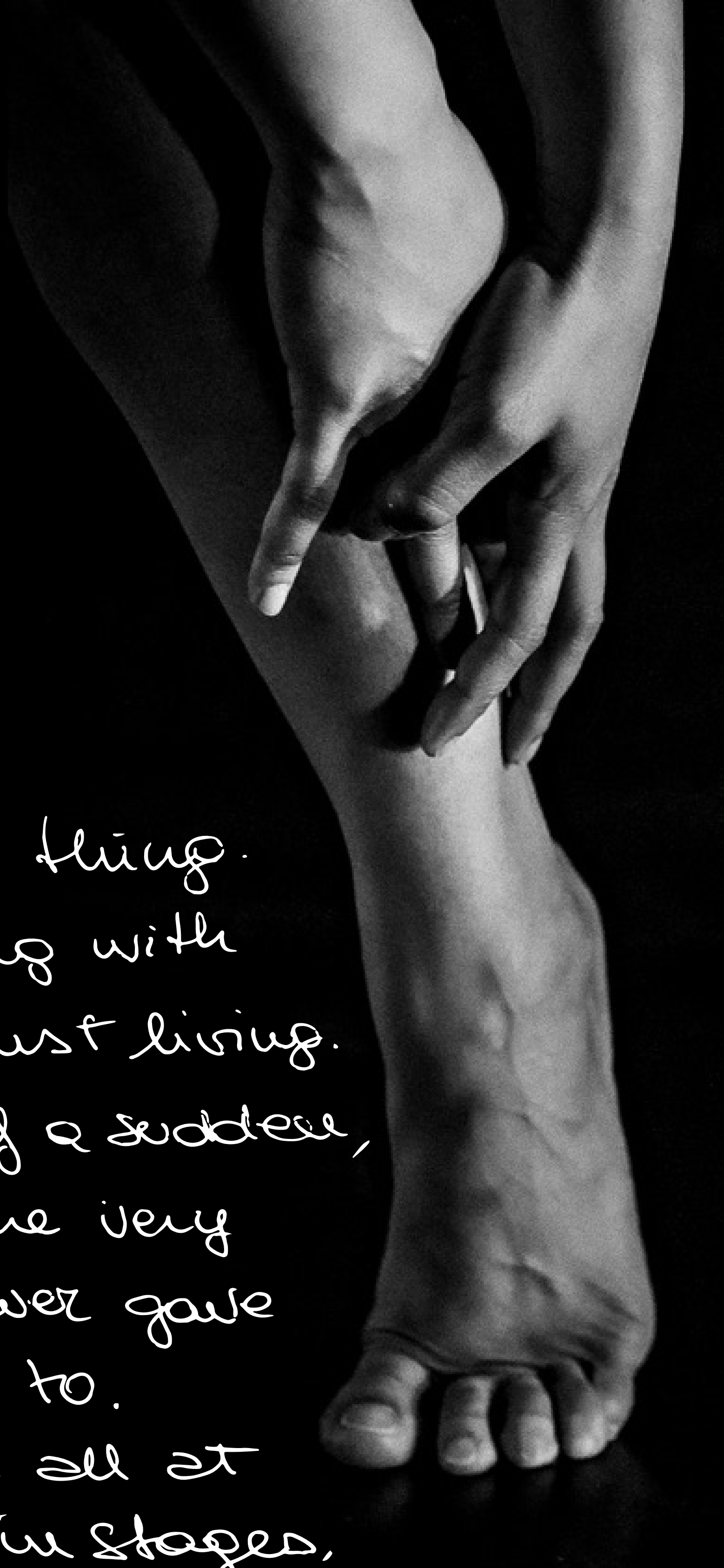
Why would I?

I was healthy

Almost **90%** never heard about scleroderma before the first symptoms or signs.

More than **36%** learned about it through the rheumatologist, via internet or social media **(11.5%)** and **5%** via patient organisations.

Survey respondents indicated the following first symptoms: decreased flow to the fingers **(17,35%)**, swollen fingers **(12,51%)**, fatigue **(11,85%)**, pain **(9,66%)**, skin thickening **(6,25%)**.



Was healthy.
You see, that's the thing.
Before you're living with
a disease, you're just living.
Then one day, all of a sudden,
you start to lose the very
movement you never gave
a second thought to.
It doesn't happen all at
once, coming on in stages,
but the strange swelling of
joints combined with an
inexplicable fatigue starts
to make you think it
might be time to see a doctor.

Trips to the doctor are funny things.

We like to think that if you go to a medical professional, you come out with a little piece of paper that tells you how to stop hurting.

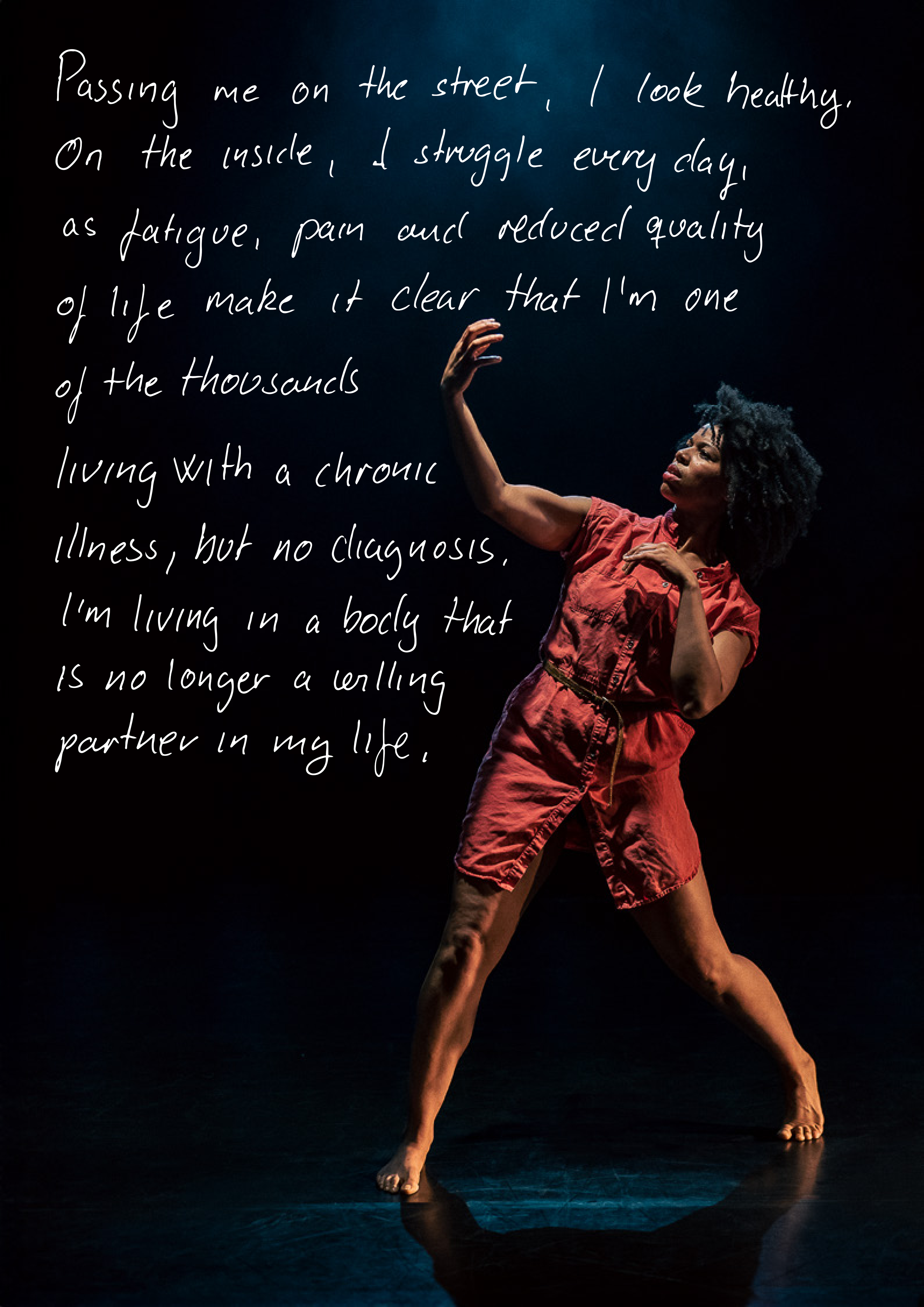
What if they don't know how to make you better?

But what if you leave with no more information than you went in with? What if you are faced with a frustrating lack of progress and the prospect of waiting years to receive a diagnosis?

50% of all survey respondents do not receive an accurate diagnosis within a year of first experiencing symptoms

The **38%** of the survey respondents who did not get a correct diagnosis were mainly diagnosed with autoimmune thyroid disease, carpal tunnel, lung disease and fibromyalgia while another **15%** were diagnosed with anxiety or depression.

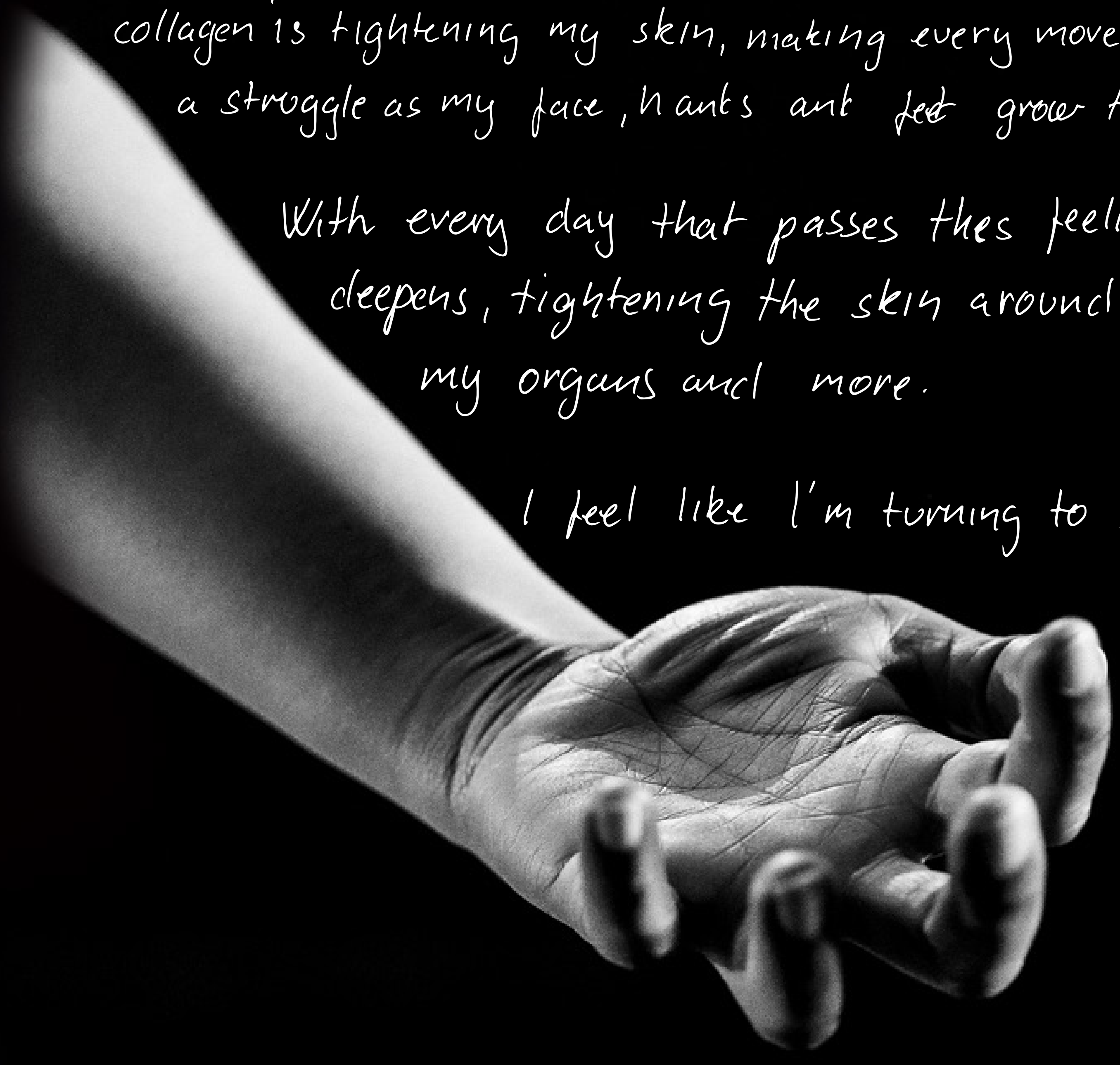
Passing me on the street, I look healthy.
On the inside, I struggle every day,
as fatigue, pain and reduced quality
of life make it clear that I'm one
of the thousands
living with a chronic
illness, but no diagnosis.
I'm living in a body that
is no longer a willing
partner in my life.



I didn't know it at the time, but the overproduction of
collagen is tightening my skin, making every movement
a struggle as my face, hands and feet grow tight.

With every day that passes this feeling
deepens, tightening the skin around
my organs and more.

I feel like I'm turning to stone.



25% indicated strong difficulties in coping with everyday physical activities such as walking, climbing stairs or carrying groceries while **47%** reasonably manage these activities.

More than **40%** of the survey respondents indicated pain as interfering with normal work both inside and outside the home.

Systemic Sclerosis.

I'd never even heard of it until a specialist told me I had it.

Now I understand there is a reason that explains why my breathing has become more and more difficult.
A cause for the fact that I'm struggling to climb stairs without running out of breath.

Diagnosis might be an answer but it also brings up more questions I don't know the answer to.

How do I live with an incurable disease?

50% of survey respondents said they did not receive an accurate diagnosis within a year of first experiencing symptoms.

80% of the survey respondents indicated that they received information about the disease at diagnosis but only **60%** indicated that the information was easy to understand.

I have no clear path on what to do next, every resource I turn to presents me with a tidal wave of worst-case scenarios.

My friends and family try to empathise but they don't understand.

If I hear another person tell me I don't look ill, I'm going to SCREAM.

How can I blame them? at first glance I might appear healthy, on certain days I might even feel it, but first glances can be massively deceiving.

I've never felt so ALONE ☹

60% of survey respondents claimed to isolate themselves, reducing time spent at work and other activities. Isolation often arises due to issues expressing concern regarding the disease, family and friends' struggles empathising with patients, and inadequate support from healthcare professionals.

But I'm not alone.
I'm one of the many who live with Scleroderma,
one of the many who made it to a diagnosis
and beyond. And WE are many.
A community of people who searched for an answer.
A community of people to support each other

whatever the future
may hold ♥

80% of survey respondents indicated to have access to high quality and easy to read educational material about scleroderma obtained on internet **(30%)**, from patient organisations **(23%)**, from a scleroderma centre **(12%)** or from a specialist **(11%)**.

70% of the survey respondents indicated to have access to multidisciplinary teams (MDTs) while the collaboration between MDTs and the general practitioners is indicated in **40%** of the cases.

Not every day is good, in fact, many of them
are not.
And while there are some things that will never
be the same, I am not suffering from my illness
I am Living with it.

My future may be uncertain at times.

But I am not afraid.

All survey respondents indicated barriers faced in receiving drug treatment such as late diagnosis **(23%)**, lack of referral to a specialist or an expert centre **(17%)** or long waiting time, the pandemic, multiple examinations **(40%)**.

70% of survey respondents indicated that they never received information about the opportunity to take part in a clinical trial.

More than **80%** of survey respondents indicated that physical health and emotional difficulties impacted their ability to socialise with family and friends.

More than **50%** noted extended periods of absence from work: 30% reported between two weeks and a month, with 20% indicating over a month.

While my life is no longer the
same, it's still my life to live!

My schedule has more doctors' appointments
than ever before, and I know I will be
faced with difficulties that I'm only
just beginning to comprehend.

My work life has changed,
my relationships have
changed.

But I have changed too.
I've found my light!

I am not my disease.
I am still me.
If I can't run, I'll walk.
If I can't climb, I'll step.
If I can't dance, I'll keep moving.

You just met me.
You don't know my name.

Let me help you with what I learned
on my journey.

FESCA calls upon policymakers to respond to unmet needs of scleroderma patients and improve their quality of life by taking action to:

1. Ensure signs and symptoms are recognised early, allowing prompt referrals to specialised care and treatment access.

2. Prioritise and fund access to psychological support and other non-drug treatments as part of treatment plans.

3. Implement adequate labour market policies for those with chronic conditions, ensuring participation in society and financial independence, whilst preventing work-related issues.

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We would also like to thank those living and working with Scleroderma who hand-wrote this book and helped us bring it to life.