All.Can Spain

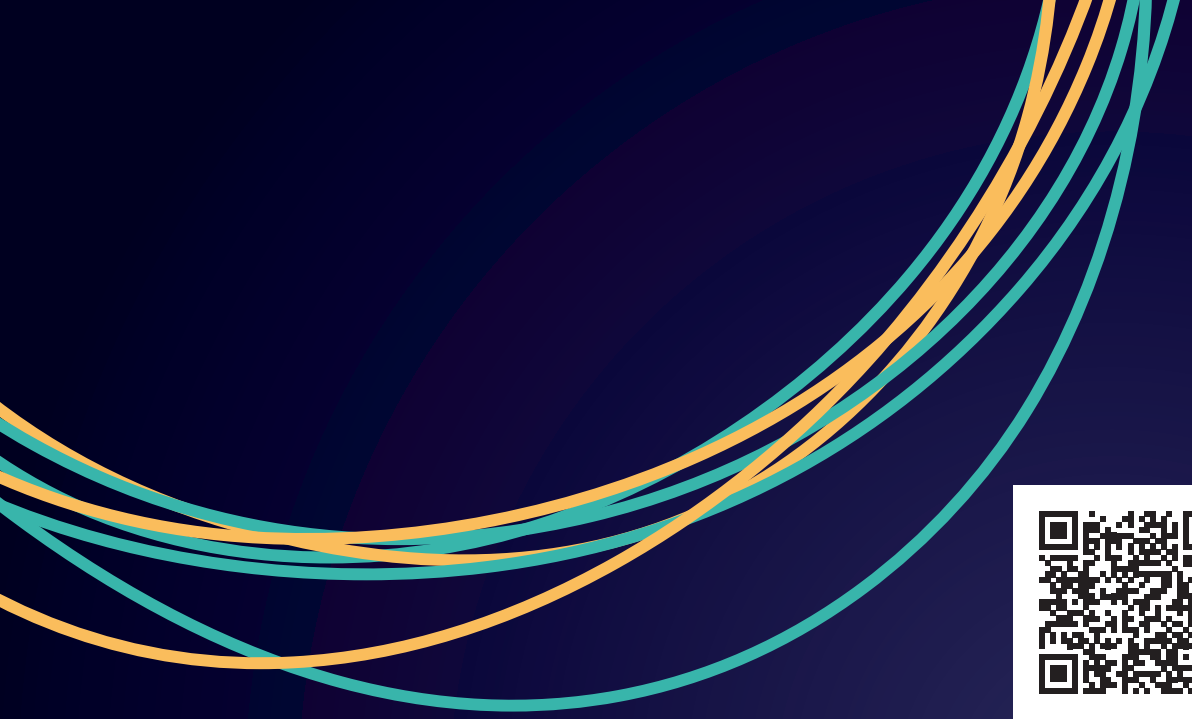
Changing cancer care together

Executive Report

3rd report of the Scientific Committee of All.Can Spain

Long-term cancer survivors, an obstacle course

6 Recommendations to improve the management of long-term cancer survivors



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After cancer, restoring personal and professional life doesn’t happen on its own. True reintegration requires understanding, assistance, and spaces adapted to this new phase.

Enric Barba

I. ABOUT ALL.CAN SPAIN

All.Can Spain, the Spanish chapter of the international platform against cancer All.Can, has the support of leading institutions, scientific societies and patient associations in our country in the field of cancer.

The Spanish chapter of All.Can has the vocation **to identify and promote the implementation of concrete proposals** that help **to overcome inefficiencies** in the approach to cancer, starting with those that will bring the greatest benefits for a coordinated and quality care for cancer patients.

To this end, the **Institutional Members** of the platform have formed a **Scientific Committee** which, recognising the **great advances made by the National Health System** in recent years and decades, have identified a series of **recommendations that would make a decisive contribution to improving the experience of long-term cancer survivors.**

This report concludes **the trilogy of studies conducted by All.Can Spain,** which address various stages of the oncology care pathway: from suspected cancer to diagnosis, diagnosis and treatment, to the management of long-term survivors. Each of these reports has been developed under the platform's fundamental principle: to identify inefficiencies within the care system and, based on this diagnosis, propose recommendations that optimize the patients' experience across all these phases.

All.Can Spain has, as of the finalisation of this document, the support of **Bristol Myers Squibb, Amgen y Merck Sharp & Dohme.**

Scientific Committee

The **Scientific Committee of All.Can Spain** is composed, as of the finalisation of this document, of the following Institutional Members (in alphabetical order of the institution):

- **Dr. Rafael López,** President of the Spanish Association for Cancer Research (ASEICA) and Head of the Medical Oncology Department at the University Hospital Complex of Santiago de Compostela.
- **Mr. Antonio Blanes,** Director of Technical Services of the General Council of Official Associations of Pharmacists (CGCOF).
- **Ms. Guadalupe Fontán,** Coordinator of the Spanish Institute of Nursing Research of the General Council of Official Nursing Associations of Spain (CGE).
- **Dr. Luis Paz-Ares,** member of the Board of the Foundation for Excellence and Quality in Oncology (Fundación ECO) and Head of the Medical Oncology Department at Hospital 12 de Octubre.
- **Dr. Mariano Provencio,** Corresponding Member of the Royal National Academy of Medicine (RANM) and Head of the Medical Oncology Department at the Hospital Puerta de Hierro.
- **Dra. Ana Rodríguez,** regular collaborator of the Spanish Society of Health Executives (SEDISA), distinguished and former Director of Strategy and Projects at the Catalan Institute of Oncology and the Catalan Health Institute.
- **Dra. Fátima Santolaya,** Head of the Working Group on Palliative Care and Oncology of the Spanish Society of General and Family Physicians (SEMG).

On the patients' side, the Scientific Committee has the following Institutional Members:

- **Mr. Bernard Gaspar,** President of the Spanish Association of People Affected by Lung Cancer (AEACaP).
- **Mr. Roberto Saldaña,** Director of Innovation and Citizen Participation of the European Patients' Academy EUPATI.
- **Mr. Enric Barba,** patient advocate de la Asociación Melanoma España.

II. CONTEXT AND INCIDENCE OF CANCER IN FIGURES

In 2023, **cancer became the leading cause of death in Spain,** surpassing diseases of the circulatory system for the first time. It is estimated that by **2025 approximately 296,103 new cases of cancer will be diagnosed,** representing a 3.3% increase compared to 2024. Likewise, the annual incidence is expected to exceed 350,000 cases by 2050.

In 2025, it is estimated that **1 in 20 individuals in Spain will be a long-term cancer survivor,** highlighting the importance of adapting healthcare and social systems to this emerging reality, which poses new challenges. This document presents the main conclusions of the report elaborated by All.Can Spain, which identifies the pillars of **comprehensive, personalized care focused on quality of life,** as well **as concrete proposals to advance** towards a care model that looks **beyond medical discharge.**

CANCER INCIDENCE IN FIGURES

+0,2%
Increase in cancer deaths

237,8
Deaths from tumors per 100,000 inhabitantss

26,6%
Of all deaths

296.103
New cancer cases diagnosed by **2025**

+18,2%

350.000
New cancer cases diagnosed by **2050**

- **Define better to care better:** Following a literature review, an updated and humanized understanding of the term "long-term cancer survivor" has been adopted, viewing survivorship as a process that begins at diagnosis and may last a lifetime, including those living with the disease in its chronic phases with a good quality of life.
- **A system that looks beyond medical discharge:** Cancer care must extend beyond medical discharge, addressing the physical, emotional, and social challenges of long-term survivors, while rectifying inefficiencies in long-term follow-up and support.
- **It is time to move toward a comprehensive and personalized model:** All.Can Spain proposes the development of a National Plan for Long-Term Cancer Survivors that provides integrated, personalized, and coordinated care, including individualized follow-up, psychosocial support, and the promotion of healthy habits.
- **Living with quality:** because there is much life after cancer. Living well after cancer requires supporting social and professional reintegration, guaranteeing the right to be forgotten, and advancing towards a model of care focused on life, not just the disease.
- **Information to transform:** the lack of specific data on long-term cancer survivors limits the capacity for improvement. It is proposed to create a national information system on long-term cancer survivors, enabling the design of evidence-based policies and continuous monitoring, leveraging technologies such as apps, wearables, and AI.
- **Strengthening the pillars of healthcare:** Strengthen nursing, Primary Care, and pharmacy as key pillars of close and continuous care, promoting coordination between levels of care and new models such as home monitoring and day hospitals.

6 Long-term cancer survivors, an obstacle course

Recommendations to improve the management of long-term cancer survivors

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Development and Implementation of **Individualized Follow-Up Plans for Cancer Survivors.**

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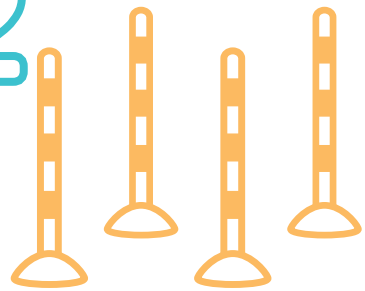

Promotion of **therapeutic adherence and healthy lifestyle habits as key elements** for relapse prevention.

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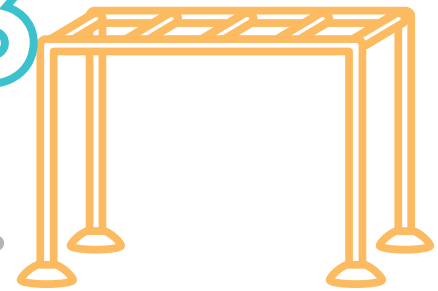

Creation and Implementation of a **National Information System for Long-Term Cancer Survivors**.

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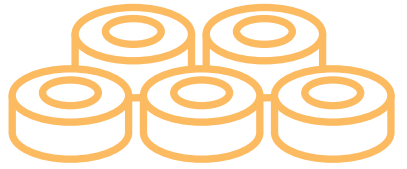

Programs to **support social reintegration** implementation.

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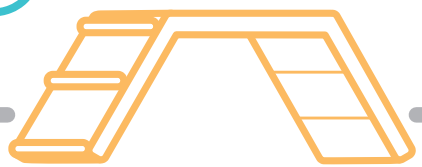

Empowerment of key professionals in Primary and Hospital Care.

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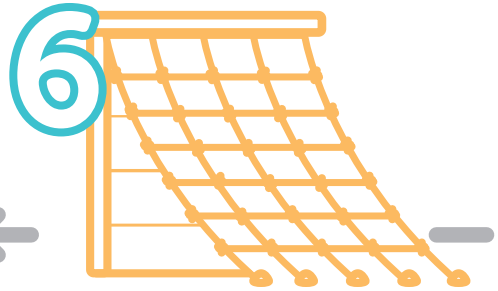
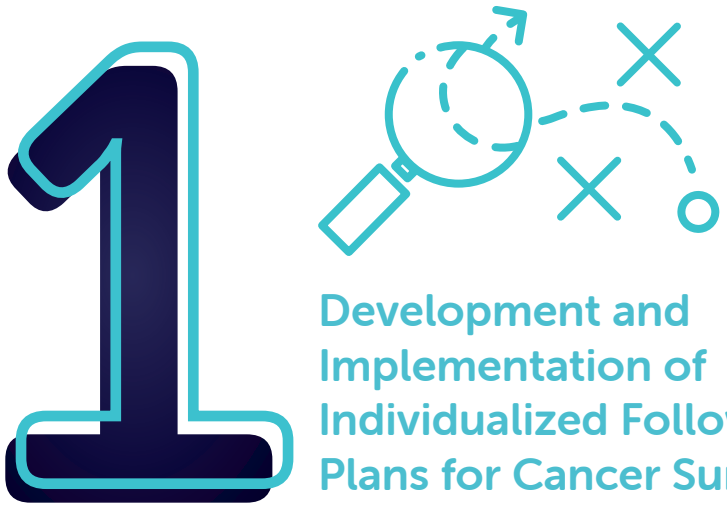


Improvement of communication and **building of a strong psychosocial support** system for patients.



Development and Implementation of Individualized Follow-Up Plans for Cancer Survivors.

For the early detection of relapses, improving prognosis and therapeutic options.

The need to develop individualized follow-up plans for patients after completing their cancer treatment is essential, as they serve as a crucial roadmap in the transition from active treatment to long-term survivorship, as outlined in Objectives 31 and 32 of the National Health System's Cancer Strategy.

One of the fundamental components of these plans is patient monitoring for the early detection of relapses, with the aim of improving prognosis and treatment options. To achieve this, they also seek to ensure a fast-track pathway back into the healthcare system in the event of symptoms or suspicions, avoiding delays in access.

The role of professionals such as physicians, nurses, and continuity-of-care pharmacists, as well as case manager nurses who are familiar with the patient's medical history and can effectively coordinate the necessary care, is crucial to ensuring continuity of care

It is essential to monitor long-term cancer survivors for the early detection of relapses or the development of new cancers.

Establishing a common model for the entire National Health System, institutionalized and accessible to all patients, is crucial for improving the implementation of these follow-up plans, emphasizing the importance of establishing follow-up protocols between Primary and Hospital Care.

Finally, these plans must be adaptable to each patient, considering factors such as the progression of treatment-related aftereffects and changes in personal circumstances. It is therefore essential to consider dynamic tools subject to continuous review and updating, such as the creation of a national epidemiological surveillance system to quantify and characterize long-term cancer survivors in Spain.

Promotion of therapeutic adherence and healthy lifestyle habits as key elements for relapse prevention.

With the aim of reducing the risk of relapse.

The promotion of healthy habits and patient engagement in their cancer treatment are key aspects in reducing the risk of relapsing and improving quality of life. Therefore, it is crucial to encourage a healthy lifestyle, maintain treatment adherence, and adopt preventive measures.

To ensure better treatment adherence, case manager nurses, specialists in family and community care, community pharmacy, and Primary Care play a key role.

Between 30% and 50% of cancers could be prevented by reducing risk factors, such as tobacco control, maintaining a healthy weight, engaging in physical exercise, following a healthy diet, limiting alcohol consumption, and participating in early detection programs.

Another key practice to promote therapeutic adherence is the use of digitalization technologies such as AI, telemonitoring, dedicated follow-up phone lines, and digital platforms like Personalized Care Models (PCMs). These tools enable stratified and more participatory monitoring, facilitate shared decision-making, and provide care tailored to the risk level and needs of the long-term survivor.

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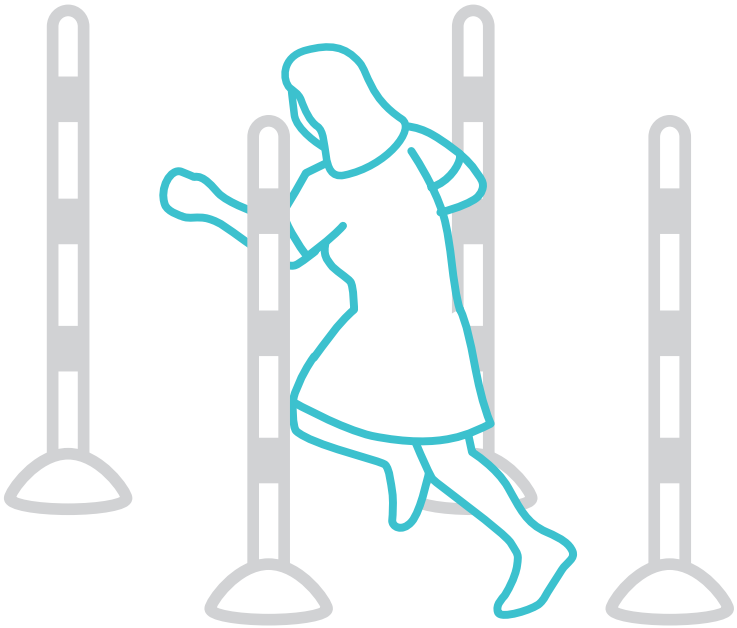


3

Creation and Implementation of a National Information System for Long-Term Cancer Survivors.

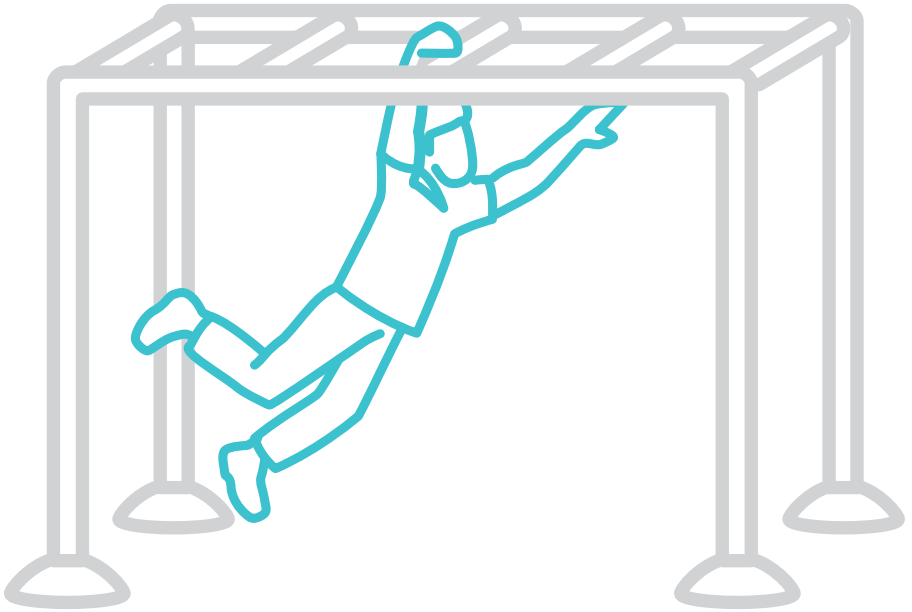
Essential for the development of strategies tailored to each patient.

Currently, up-to-date cancer survival data is available for only 27% of the Spanish population, significantly limiting knowledge about the long-term health of patients. At a national level, there is still a lack of precise epidemiological information on the total number of cancer survivors and their impact on different areas, such as work, psychological well-being, and social life.

The lack of information regarding the long-term physical, psychological, and social consequences of cancer is the main barrier underlying this large-scale data gap. Furthermore, current follow-up models have not been updated and present limitations in addressing these needs. As a result, a large percentage of long-term survivors lack specific care protocols.

For this reason, it is crucial to count with a national information system on long-term cancer survivors that collects and centralizes detailed, anonymized patient information in a registry, in order to improve healthcare planning, personalized follow-up, and the development of statistical models.

The incorporation of advanced digital tools and AI models for data analysis into this system, along with the development of Clinical Practice Guidelines (CPG) specific to cancer survivorship, are key to reducing variability in care and supporting evidence-based clinical decision-making.



There is a significant lack of specific data (updated cancer survival data only exist for 27% of the Spanish population) and limited knowledge about their long-term health.

Initiatives such as the specific registry for long-term childhood cancer survivors at Hospital Niño Jesús or the Observatorio del Superviviente de Cáncer demonstrate the benefits of having structured follow-up systems, contributing to improved personalized care and quality of life for long-term survivors.

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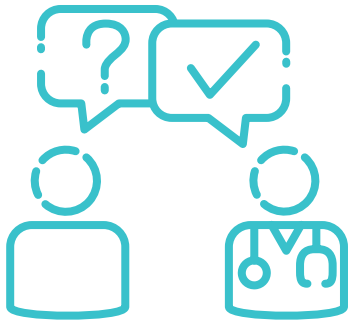

Improvement of communication and building of a strong psychosocial support system for patients.

With the aim of ensuring that treatments and follow-ups align with best clinical practices.

The implementation of a multidisciplinary approach, enabling professionals to collaborate and ensure more efficient management of patients' needs, is essential to guarantee comprehensive and personalized care, allowing treatments and follow-ups to align with best clinical practices.

It is essential to strengthen patient-centered care by promoting active participation and ensuring health education, psychosocial support, and accessibility to services through a coordinated and multidisciplinary care model.

Misinformation also poses a barrier, making it crucial for psychosocial support systems to include mechanisms that provide and facilitate access to scientifically validated information.

For optimal coordination and follow-up of oncology patients, it is essential to equip Primary Care professionals with effective tools, as well as implement integrated care processes that optimize communication and the efficiency of follow-up.

It is essential to provide primary care professionals with more effective tools to facilitate their work in coordination and follow-up.

5

Empowerment of key professionals in Primary and Hospital Care.

To ensure comprehensive and high-quality care for cancer survivors.

To ensure comprehensive and high-quality care, it is crucial to foster collaboration among different professionals such as nurses, Primary Care physicians, and both Primary Care and Community pharmacists.

The role of case manager nurses (CMN) is key in providing continuous care to oncology patients. Their involvement has proven essential in coordinating the care process comprehensively, managing available resources, processing tests, and ensuring continuity of care.

Integrating Primary Care into patient follow-up is fundamental, as the care of long-term survivors should not solely rest within the hospital setting but be addressed collaboratively, including other healthcare professionals.

Another key element within the care network is community pharmacy, which, thanks to its widespread presence, accessibility, and potential, offers personalized care within the patient's everyday environment.

Care for long-term survivors should not rely solely on the hospital setting but should be approached from a multidisciplinary perspective.

6

Programs to support social reintegration implementation.

To address the impact that cancer has across all dimensions.

Cancer not only affects the physical health of those who suffer from it but also has a significant impact on social, occupational, and economic aspects, such as loss of productive capacity and the challenges long-term survivors face in regaining functional ability.

More than 20% of survivors are in a situation of occupational risk, and 37.7% of unemployed survivors do not receive unemployment benefits, highlighting their economic vulnerability. Regarding the economic impact of cancer at the national level, the figure amounts to 19.3 billion euros annually.

Currently, the social component remains an under addressed aspect, overlooking key factors to improve these patients' quality of life, such as reintegration into daily life, emotional support, and social adaptation after the illness. A notable advancement was the approval of the 'right to be forgotten' for cancer survivors, which prevents requiring the patient's oncological medical history once five years have passed since the end of radical treatment without relapse.

The role of secondary patients, such as family members, is also fundamental, as they assume physical and emotional responsibilities throughout the oncological process. Therefore, it is essential to have specific support programs directed at this group.

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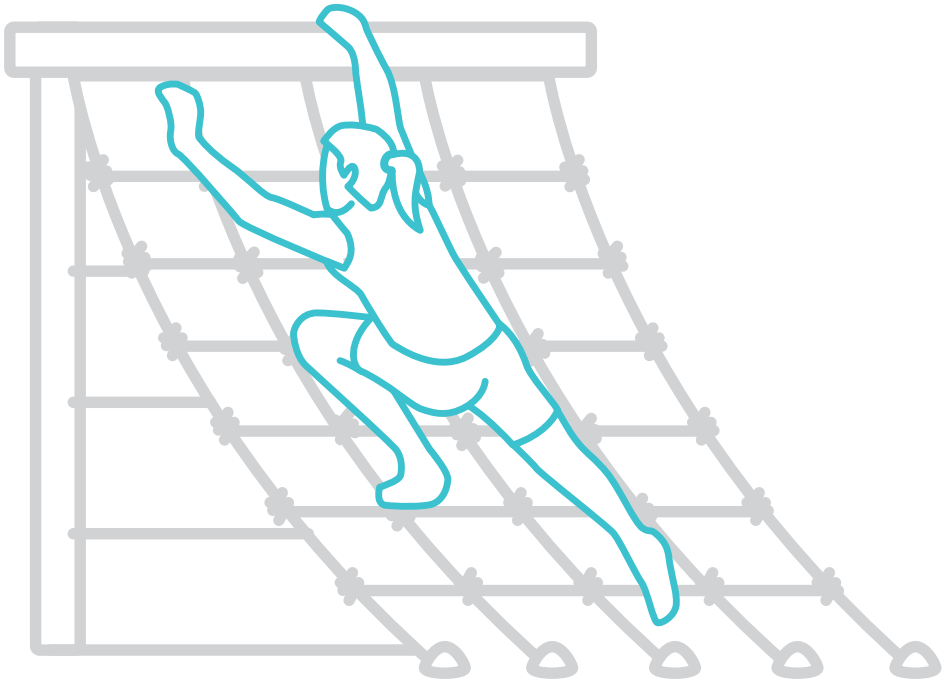
> **It is often forgotten that behind every patient there is someone who cares, supports, and also suffers. Caregivers need to be seen and supported just as much as those going through the illness.**
>
> Bernard Gaspar



We hope you have found this report as a useful and inspiring initiative.

THANK YOU

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All.Can Spain

With the collaboration of:

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