



# Eurocarers work with and for young carers

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Childhood Research Network, Stockholm, 18-19 September 2018



# The Eurocarers Network

European network of carers' organisations and relevant research institutes. 67 members from 25 European countries.

## Our mission

Ensure that the significant contribution made by informal carers to health and social care systems and the economy as a whole is recognised and safeguarded through adequate support.

## Who are the informal carers?

Any person who provides care - usually unpaid - to someone with a chronic illness, disability or other long lasting health or care need, outside a professional or formal framework.



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# Young carers: definition and numbers

Young carers are children and young persons under 18 who care, unpaid, for a family member with an illness or disability, mental health condition or addiction.

They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult.

## Young adult carers

18– 24 years

## Adolescent young carers

15- 17

### UK

8% young carers (11-18 years)

### Sweden

7% young carers (14-16 years)

### The Netherlands

6% young carers (13-17 years)

### Switzerland

7,9% young carers (10-15 years)

### Italy

7,3 % boys  
6,9% girls  
(15-24 years)



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# Young carers: a “hidden army” of carers

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- ✓ Problem in self-identification
- ✓ Fear of being judged or misunderstood by their peers, teachers or service providers
- ✓ A parent may discourage or disallow a young carer accessing services, because of privacy concerns, fears of child protection intervention (separation), cultural norms or even denial of existing circumstances
- ✓ Fear to appear not good enough in providing support for their family member
- ✓ Stigma (e.g. when cared for person has mental illness or substance dependency)
- ✓ Uncertainty about who to talk to
- ✓ Believe that nothing will change if they disclose their caring responsibilities
- ✓ Service providers tend to focus on the cared for person
- ✓ Wider community is not aware of specific services for young carers (if any)



Young carers remain unidentified and they do not receive the support they need

# The impact of caring

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## Mental health and wellbeing

Young carers can gain satisfaction from caring and experience self-esteem, empathy, maturity. Yet, having to reconcile new life challenges (e.g. entering the labor market, attending university courses, starting their own family) with caring responsibilities can be overwhelming. The pressure associated with caring can be considered as a risk factor for mental ill-health.

## Education

In the absence of adequate support, caring can have a negative impact on young carers' education, as it can entail under-achievement, absence and drop-outs. These short term effects can cause low employability in the long term.

## Social Life

Young carers might have less dedicated time for personal development and leisure. They can also become victim of social stigma and bullying, with the result of a higher life course social exclusion.

# A continuum of children's caring

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## CARING ABOUT

Low levels of caring and responsibility

Most children

'Routine' levels and types of caregiving, including some help with instrumental tasks of daily life

Little evidence of negative outcomes

## TAKING CARE OF



Caregiving tasks and responsibilities increase in amount, regularity, complexity, time involved, intimacy and duration

## CARING FOR

High levels of caring and responsibility

Few children

'Substantial, regular and significant' caregiving, including considerable help with instrumental tasks of daily life

Evidence of significant negative outcomes



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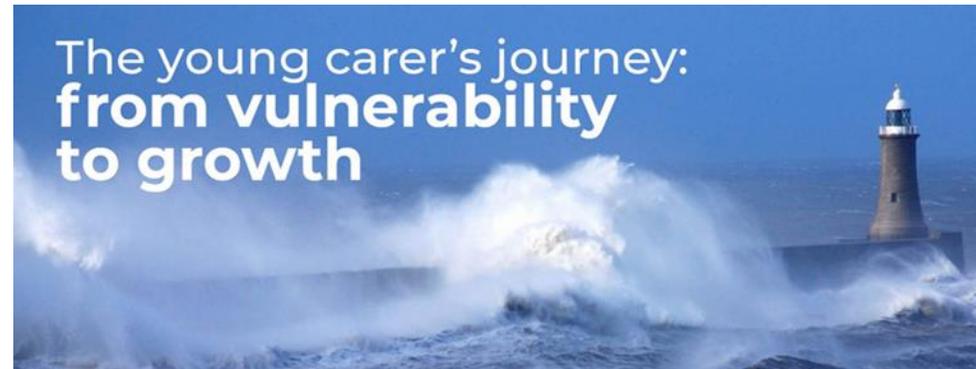
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# Why do we need to support young carers?

## Human rights argument

Young carers should benefit from equal opportunities to realise their full potential through social inclusion, education and employment.

They are a **vulnerable groups with specific needs** → Young carers have the right to **extra, tailored positive actions (reasonable accommodations)** to ensure that they have access to education and employment, to the highest attainable standard of physical and mental health, to participation, to an adequate standard of living and to a family life be respected.



## Economic argument

Investing in young people is a **social investment**  
**Early school leaving** is an obstacle to economic growth and employment  
**Poor mental health is a cost** for societies

# Classification of in-country awareness and policy

Level	Characteristics	Example
<b>1</b> Incorporated	<ul style="list-style-type: none"><li>• Extensive awareness at all levels of government and society of the experiences and needs of young carers</li><li>• Sustained and sustainable policies and interventions aimed at meeting young carers' needs and promoting their health, well-being and development</li><li>• Responses and law built on a foundation of reliable research evidence and clear legal rights</li></ul>	<b>None</b>
<b>2</b> Advanced	<ul style="list-style-type: none"><li>• Widespread awareness and recognition of young carers amongst public, policy makers and professionals</li><li>• Extensive and reliable research base, and growing</li><li>• Specific legal rights (national)</li><li>• Extensive codes and guidance for welfare professionals and national and local strategies</li><li>• Multiple dedicated services and interventions nationwide</li></ul>	<b>United Kingdom</b>

Level	Characteristics	Example
<p><b>3</b> Intermediate</p>	<ul style="list-style-type: none"> <li>• Some awareness and recognition of young carers among public, policy makers and professionals</li> <li>• Medium-sized research base, and growing</li> <li>• Partial rights in some regions</li> <li>• Small but developing body of professional guidance</li> <li>• Some dedicated services and interventions, mostly local but a few nationwide</li> </ul>	<p>Australia Norway <b>Sweden</b></p>
<p><b>4</b> Preliminary</p>	<ul style="list-style-type: none"> <li>• Little public or specialist awareness and recognition of young carers</li> <li>• Limited research base, but growing</li> <li>• No specific legal rights but other laws may be applicable</li> <li>• Few, if any, dedicated services or interventions at national or local levels</li> </ul>	<p>Austria Germany New Zealand</p>
<p><b>5</b> Emerging</p>	<ul style="list-style-type: none"> <li>• Growing public or specialist awareness and recognition of young carers</li> <li>• Small but growing research base</li> <li>• No specific services or interventions for young carers, but other services might be applicable</li> </ul>	<p>Belgium; Ireland Italy Sub-Saharan Africa Switzerland Netherlands; US</p>

Level	Characteristics	Example
<p style="text-align: center;"><b>6</b> <b>Awakening</b></p>	<ul style="list-style-type: none"> <li>Embryonic awareness of young carers as a distinct social group</li> </ul>	<p style="text-align: center;">Greece Finland UAE France</p>
<p style="text-align: center;"><b>7</b> <b>No response</b></p>	<ul style="list-style-type: none"> <li>No apparent awareness or policy response to young carers as a distinct social group</li> </ul>	<p style="text-align: center;"><b>All other countries?</b></p>

Leu, A., & Becker, S. (2016). A cross-national and comparative classification of in-country awareness and policy responses to 'young carers'. *Journal of Youth Studies*, 1–13



# Eurocarers commitment to young carers

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## Research

- Me-We Project
- Edy-Care Project

## Awareness raising/Advocating for change

- Events on young carers
- Press Releases/Policy briefings
- Dialogue with MEPs
- A campaign to support young carers developed by the Eurocarers Young Carers working Group



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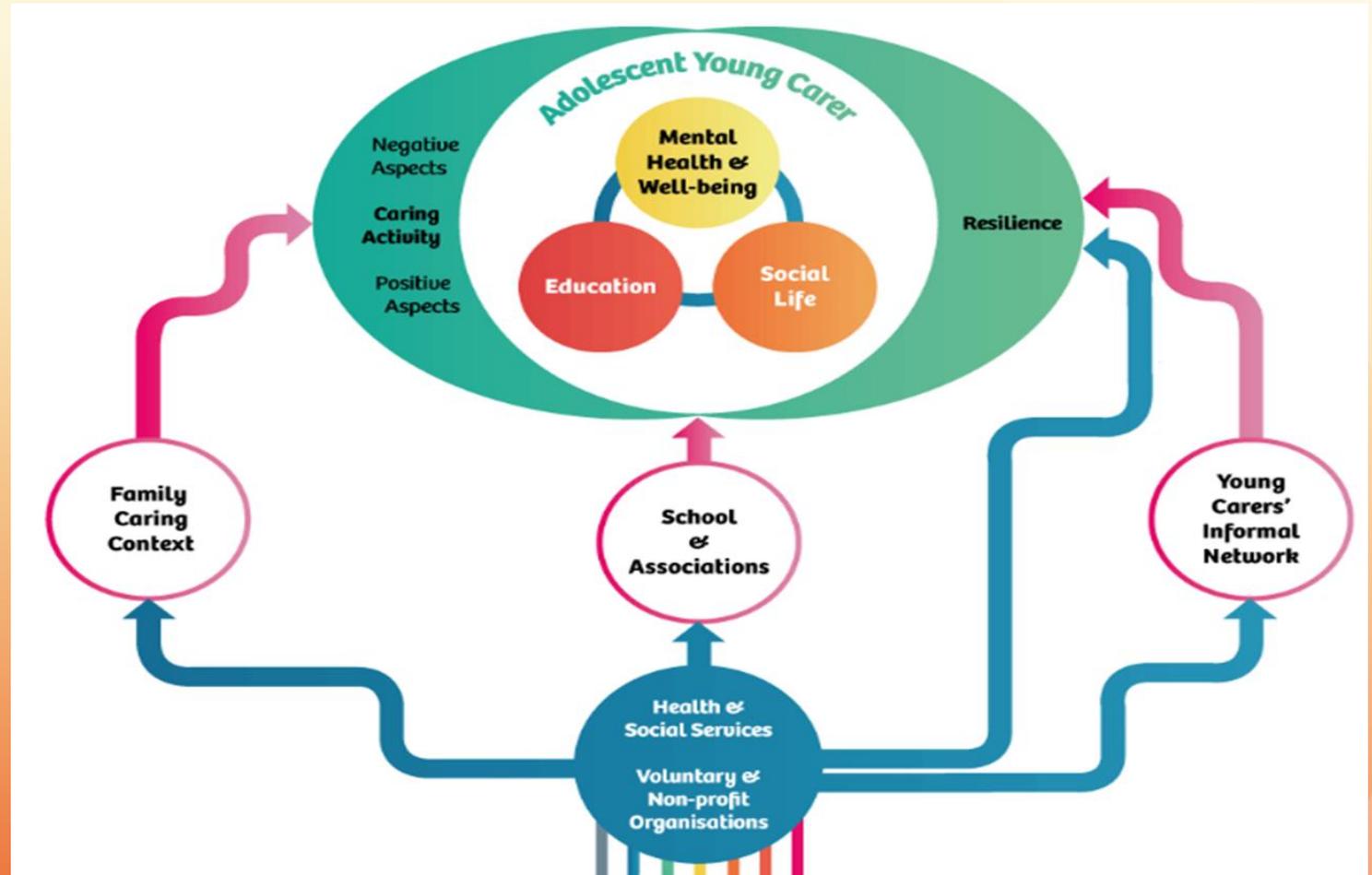


# Me-We Project: Psychosocial Support for promoting mental health and wellbeing among adolescent young carers in Europe

# Towards improved resilience and enhanced social support for adolescent young carers

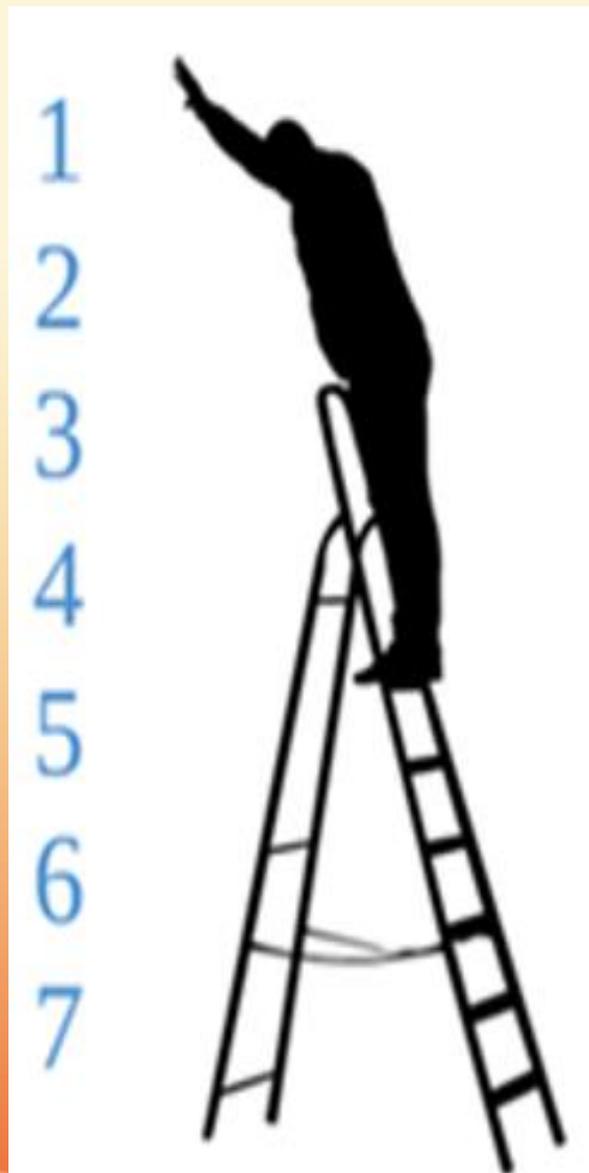


Aim: to mitigate the risk factor of being an adolescent young carers by empowering the young with **improved resilience** (the process of negotiating, managing and adapting to significant sources of stress or trauma) and **enhanced social support** (from family, school, peers, services).





# The Me-We Project Consortium



## Objective 1: Systematise knowledge

Adolescent Young Carers' profiles,  
needs and preferences

National policy, legal and service  
frameworks

Good practices, social innovations &  
evidence

## Objective 2: Co-design, develop and test with AYCs an effective framework of interventions

Participatory co-  
design

Implementation

Evaluation and  
impact

## Objective 3: Carry out wide knowledge translation actions

Knowledge translation, dissemination and communication



## Individual level

Short & medium term

Improved mental well-being in the targeted group of young people

Long term

Contribution to (a) reducing school and college/university dropout in the short term, (b) strengthening personal confidence and cognitive function, (c) improving educational efforts and (d) enhancing employability.

## Societal level

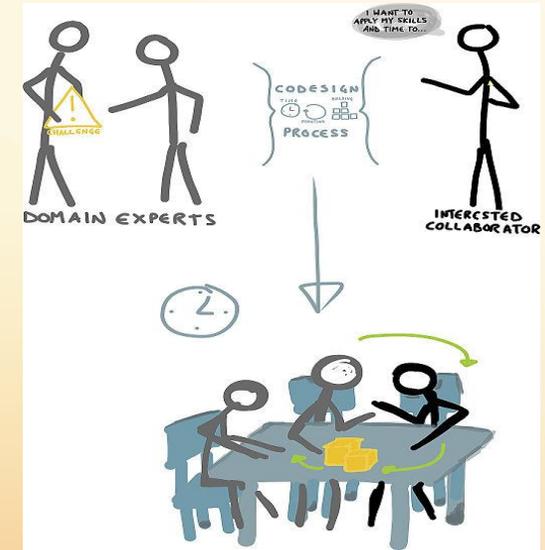
The innovative interventions will create (a) a strong evidence base for mental well-being promotion programmes in Europe, contributing to (b) greater health equity and (c) improved societal benefits.

Preventative strategies are established which have a real effect of reducing the occurrence of mental disorders and comorbidities associated with mental disorders later in life

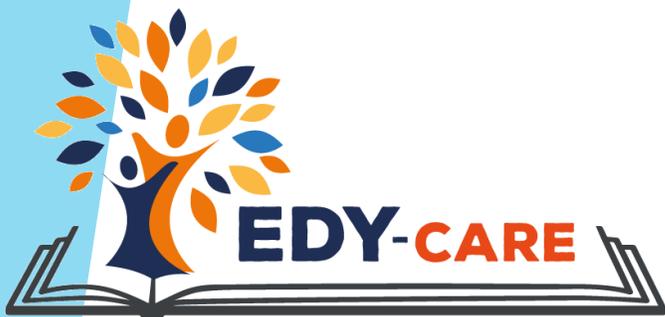
# The innovative aspects of the project



- It develops an **innovative framework of primary prevention interventions** to be tested and **adapted in 6 European countries** at different stages of awareness and development of services for adolescent young carers.
- **Co-design approach:** researchers will engage directly with and involve adolescent and adult young carers, together with carer organisations and major stakeholders through all the stages of the project.
- It implements innovative **Blended Learning Networks, i.e. heterogeneous 'communities of practice'** involving adolescent young carers and relevant stakeholders for discussing and finding best solutions.
- It is the first large scale programme to demonstrate the impact of a comprehensive primary prevention intervention for improving resilience of adolescent young carers.
- It ensures transversal knowledge sharing activities among partners and within cluster of countries.







Co-funded by the  
Erasmus+ Programme  
of the European Union

## **Innovative School Education Methodologies and tools for guaranteeing social inclusion of young carers (EDY-CARE)**

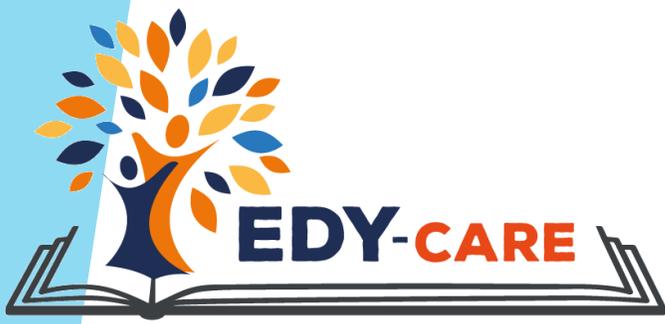


University of Ljubljana  
Faculty of Social Sciences



**Anziani  
e non solo**

Società cooperativa



Co-funded by the  
Erasmus+ Programme  
of the European Union

**Aim:** Empower teachers and other school staff (e.g., school nurses, psychologists, social workers, management) in upper secondary education to recognise adolescent young carers (16-19 years old) in classes and maximize their learning opportunities, while ensuring their social inclusion.

### Current situation

Lack of awareness among school staff about existence of young carers and their needs

→ failure in tailoring education at schools to YCs' needs

→ negative consequences on their educational attainments (as well as on their health, social inclusion and employment opportunities)



### Desired situation

School staff is empowered to identify and support YC in their educational career→

- school dropout of YCs decreases
- educational efforts and attitudes towards higher education are improved
- Young carers employability is improved

# The EDY-CARE Project objectives

- ✓ To develop an **assessment tool** that can help teachers and school staff to identify young carers;
- ✓ To develop and test a **package of educational strategies**, didactical approaches as well as organisational adjustments that schools can take to facilitate young carers and to support them in their scholastic career;
- ✓ To produce a **handbook providing guidelines and recommendations** on how teachers and school staff can work at best with young carers
- ✓ To develop a massive open online course (**MOOC**) for training teachers and school staff on the young carers phenomenon, their needs and preferences.



**Towards young carers friendly schools**

Objective	Examples of activities
<p><b>Understand:</b> the school is committed to understand and address young carers' needs</p>	<ul style="list-style-type: none"> <li>• Designating a <b>staff member</b> as <b>responsible for young carers</b>. Promotion of this individual to families, students and staff.</li> <li>• Publishing of school <b>young carer policy</b> (separate or integrated in other policies) recognising young carers as a distinct group of <b>vulnerable students</b>.</li> </ul>
<p><b>Raise awareness:</b> awareness is raised by sharing knowledge about disability, illness and YCs throughout the school</p>	<ul style="list-style-type: none"> <li>• Information on disability and young carers (and the support available to them) are available to students and school staff.</li> <li>• <b>Assembly themes or PSHE (personal social health education) lessons</b> to raise awareness of young carer issues and incorporate positive images of disability/illness (including mental illness, substance misuse and HIV).</li> <li>• Drama/arts to raise awareness of young carer issues.</li> <li>• Articles on young carers on school magazine/Young Carers Newsletter.</li> </ul>
<p><b>Identify:</b> young carers are being identified within the school</p>	<ul style="list-style-type: none"> <li>• Regular <b>training to staff</b> to identify young carers, including those who may be hidden.</li> <li>• <b>Admissions forms</b> include a statement to help identify families where someone has a long-term illness or care needs.</li> <li>• <b>Transitions plans from feeder schools</b> include sharing information regarding identified YCs entering the school.</li> <li>• <b>Home-school agreement</b> include a question asking if any extra support is needed or if there is any illness/disability in the family which may impact on the child/parents keeping to the agreement.</li> <li>• <b>The topic is presented in PSHE sessions and assemblies.</b></li> <li>• <b>Questionnaires</b> to all students, following assembly talks, inviting self-identification.</li> <li>• Checking of School Census data on pupils with disabilities, to identify sibling young carers.</li> </ul>





Objective	Examples of activities
<b>Listen:</b> YCs are listened to, consulted with and given the time and space to talk if they need to	<ul style="list-style-type: none"><li>• Young carers feed into the school council via a <b>suggestion box</b>.</li><li>• <b>Drop- in sessions.</b></li><li>• YC's views taken in consideration in school policies (e.g. Use of mobile phones).</li><li>• Disabled parents consulted on the support required to promote their inclusion and that of their children.</li></ul>
<b>Support:</b> YCs are supported within the school and signposted to other services outside the school	<b>Protect from bullyism and decrease stygma</b>
	<ul style="list-style-type: none"><li>• Staff training is provided to increase understanding of the specific issues young carers face and how and why they may trigger bullying.</li><li>• A school culture is created where difference is respected and valued by all.</li><li>• Someone is available for young carers to talk to.</li><li>• Young carers are supported and enabled to join in social activities and wider opportunities (e.g. with assistance as to transports).</li></ul>
	<b>Financial support</b>
	<ul style="list-style-type: none"><li>• A more flexible cap on the income threshold to qualify for a bursary.</li><li>• Meal vouchers, bus passes.</li></ul>
	<b>Raising young carers' aspirations towards higher education/Support transition to next steps of education</b>
<ul style="list-style-type: none"><li>• University students – with experience of caring- mentor students in secondary schools.</li><li>• Workshops to build soft skills, increase confidence, <b>dispel myths surrounding further and higher education.</b></li></ul>	
<b>Flexibility with attendance and coursework</b>	
<ul style="list-style-type: none"><li>• The school provides catch-up time for lessons and flexibility with homework for young carers who miss school or are having difficulty keeping up with their workload.</li><li>• Negotiating deadlines for homework/coursework.</li><li>• <b>Modifying timetables for the young carer.</b></li></ul>	

Objective	Examples of activities
<p><b>Support:</b> YCs are supported within the school and signposted to other services outside the school</p>	<p><b>Extra support within school</b></p>
	<ul style="list-style-type: none"> <li>• <b>Homework/coursework support.</b></li> <li>• <b>Peer support (peer mentoring;</b> young carers club).</li> <li>• <b>One to one pastoral support/counselling.</b></li> <li>• <b>Individual support plans</b> created (with family) and periodically reviewed.</li> <li>• <b>Young carer ID card.</b></li> <li>• <b>Accessibility to telephone</b> for young carers needing to check in-with home.</li> <li>• Providing access to computers and the Internet.</li> <li>• <b>Crisis planning.</b></li> <li>• Enable students to temporarily <b>learn from home</b>, by ensuring young carers have access to an online learning platform or sending notes, activities and materials.</li> <li>• Providing information about applying for special consideration, whereby teachers take into account the student’s caring responsibilities when marking assessments.</li> <li>• The school is accessible/welcoming to parents with disability and/or illness, offering additional support to enable them to attend parent’s evenings or other school events.</li> </ul>
	<p><b>Links with support outside school</b></p>
<p><b>Evaluate (monitor, review and celebrate)</b></p>	<ul style="list-style-type: none"> <li>• Schools are inspected by young carers to see how they are actually supporting young carers practically and who in the school is aware of the systems they have put in place.</li> <li>• <b>Young Carers Charter/Young carers quality standards/Young carers in schools award.</b></li> <li>• Recording of <b>young carers’ attendance and progress</b> on Inclusion Register or similar system.</li> </ul>



# Raising awareness about young carers at EU level



European Parliament Informal Carers Interest Group, Meeting on Young carers: challenges and solutions, 6 March 2018

Many governments and services providers instances are unaware rather than unwilling → we need to raise awareness (1<sup>st</sup> step)

2nd step: **focused research** in order to develop **policies** (3rd step).

Final step: **putting policy into practice.**

→ Pilot project on supporting Young Carers by MEP Pietinkainen

[Eurocarers Policy briefing on young carers](#)

[Universal Children's Day: young carers deserve full enjoyment of their rights! \(20 November 2017\)](#)

[Press Releases: European Parliament Informal Carers Interest Group calls for action to support young carers \(7 March 2018\)](#)

DG Justice Newsletter on rights of the child No 3 2018 – 18 April 2018

EUROCARERS POLICY PAPER  
YOUNG CARERS

PRESS  
RELEASE



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# Hearing from the experts: giving young carers a voice

International Young Carers Conference, Malmo, May 2017



Common challenges:  
loneliness, exclusion, no  
one listening, and often a  
sense of being different

Different  
childhood,  
same needs as  
every other  
child.

Positive side of  
caring  
responsibilities

Need for more assistance from  
professionals and from the rest  
of our surroundings

Hope that people do not only ask  
questions, but also take action  
based on the answers received  
from children and youths.

Establishment of the Eurocarers Young Carers  
Working Group



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# Working on a campaign to support young carers

Aim: To develop an EU-wide campaign to support young carers addressed to policymakers.

➔ It is important to choose the right entry points, by linking our message to priorities at EU level.

The European Pillar of Social Rights – recently approved with an interinstitutional proclamation – is the perfect policy hook.

## The Principles

## The relevance for young carers

### **Principle n. 1 – Education, training and life-long learning**

Caring responsibilities can have a negative impact on young carers' education (under-achievement, absence and drop-outs)

### ***Principle n. 4 – Active support to employment***

Young carers are more likely to be NEET (not in education, employment or training) than their peers.

### ***Principle n 11 – Childcare and support to children***

Young carers needs to be considered as children from disadvantaged backgrounds have the right to extra, tailored support so that they can have equal opportunities in enjoying social rights.

### ***Principle n. 18 – Long-term care***

By providing good quality formal LTC services to the person they care for, inappropriate caring can be avoided.



# Inclusive education – what do we need and how?

## 1) Identify young carers already in the applications and admissions process

(e.g. include a box to tick “I have caring responsibilities” in registration forms to access higher education)

## 2) Flexibility

- **Flexibility with entry requirements (make a lower offer based on the information that an applicant is a carer)**
- **Flexibility to address young carers’ special needs** (being understanding in case of lateness, absences, no homework done...)
- **Flexibility in length of training and education programmes** (shorter degrees for young carers)

## 3) Extra, tailored support

- Have more **counsellors** (with more time) you can talk to one-to-one
- **Information** on scholarship to go to college
- **Refer** students to help services (e.g. sport club, youth club) and let Ycs aware that these support services exists
- Make **school psychologist** aware of young carers and let him reach out to them

A simple action can change the life of young carers!

## 4) Raise awareness among school professionals about what being a Ycs means and what are Ycs’ needs

- Explain to teachers that it is **ok** to “discriminate” YCs (**positive discrimination**)
- Stress the need to respect **confidentiality and privacy**.

## 5) Raise awareness among peers

- Organise awareness weeks in schools, or lectures from experts.



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# Active support to employment – What do we need and how?

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Young carers have important skills!

## 1) Integrate young carers on national policies to tackle youth unemployment

## 2) Change mindsets

- Let companies become more aware of soft skills acquired by young carers (multitasking, selfless, independent, resilient, empathetic, caring, ...)
- Companies should offer trainee positions for young carers (so they can experience first hand the skills of young carers)

## 3) Extra, tailored support

- Have mentors (in employment centres) that motivate young carers to search for job

## 4) Flexibility

- Envisage possibility of Part-time or flexi-time jobs for young carers
- Have online shorter college courses for YCs so that they can easily find a job



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# Childcare and support to children – What do we want and how?

- 1) Create young carers groups in each locality to avoid that some are left out
- 2) Make easier to get information on the available support (e.g. Inform teachers and GPs and social workers about led local activities to support young carers)
- 3) Provide respite breaks for young carers
  - Organise summer camps, cinema, café, sport activities
- 4) Think about the financial cost of participation in activities
  - Provide transportation services to help young carers participate in activities
  - Envisage a reduced fee for young carers' participation in events so that exclusion doesn't occur
- 5) Raise awareness on young carers among in environments related to extra curricular activities

Don't reduce us to just being young carers. We have the right to be normal children and young people!



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# Long-term care – What do we want and how?

1) Adopt a whole family approach in LTC service provision

2) Improve quality of LTC services

3) Improve services for mental health problems, with a focus on prevention

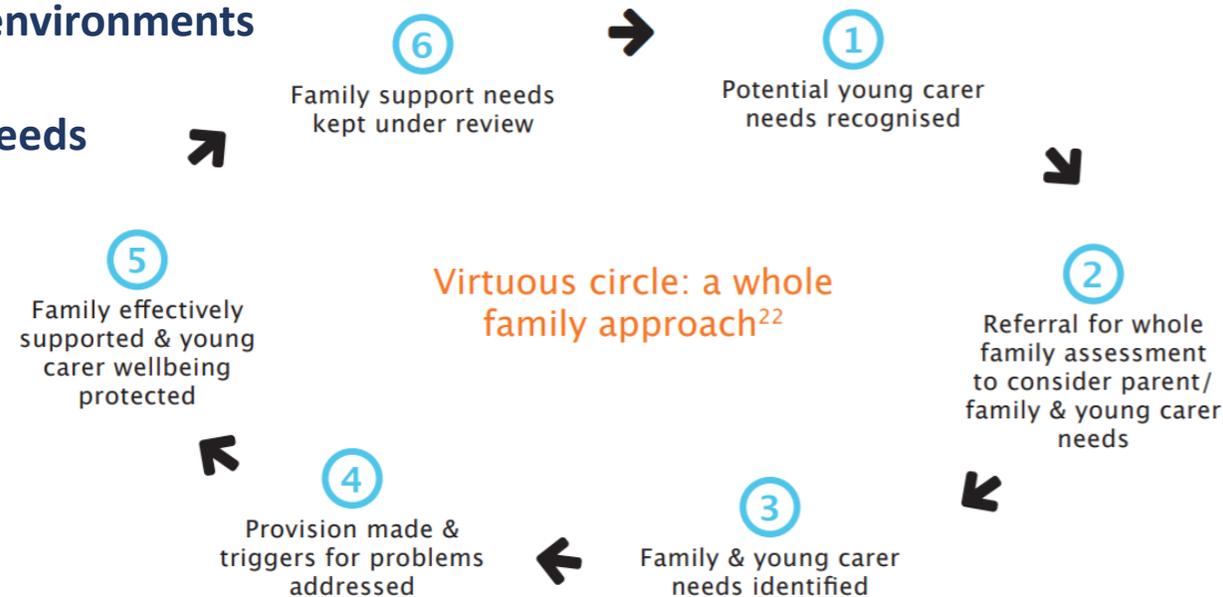
4) Have online support (e.g. video conferences) with doctors or social workers (to overcome issue of geographical accessibility)

5) Make info on support services for Ycs available in healthcare environments

6) Train home care professional to care for people with special needs

7) Strengthen collaboration between different entities & make clear to users who is responsible for what (care coordinators)

Thanks to carers, our systems save money



# Next steps

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1) Finalise the campaign addressed to policy makers.

- Ask MEPs to support our campaign.
- If they act as champions of the carer's cause, we can have the snowball effect at national level

2) Work on a parallel campaign addressed to a wider target group:

- Young carers (to help them identify as young carers and talk about their situation)
- All stakeholders gravitating around carers.

*Save  
the  
Date*

20 November 2020 - International Young Carers Conference, Brussels

Together we can achieve the desired  
change!

Thank you!

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Email: [fc@eurocarers.org](mailto:fc@eurocarers.org)

[www.eurocarers.org](http://www.eurocarers.org)

More on young carers: <http://eurocarers.org/Young-Carers>

Edy-Care Project: <http://eurocarers.org/edycare/index>

Me-We Project: <http://me-we.eu/>



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