

TOGETHER

a whole family approach
for young carers



A WHOLE FAMILY APPROACH FOR YOUNG CARERS

TOGETHER WE CARE

DIGITAL BOOKLET



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Introduction about the project

Together: A Whole Family Approach for Young Carers is an Erasmus+ funded project which aims to raise awareness of young carers and support them and their families. With partners in Germany, Italy, Greece, Belgium and Scotland, the project aims to help young carers and professionals to adopt a whole family approach where family members (including the cared-for person) are encouraged to communicate openly about the caring relationship. Our ultimate goal is to have a positive impact on families in order to support young carers; reducing the negative impacts caring responsibilities can bring and improving young people's well-being, social inclusion and community engagement.

Over the course of the two-year project, partners have developed and piloted three main outputs. The first are a series of awareness raising materials to inform children and adults about how important it is to cooperate and be supportive with each other when there is a caring responsibility in the family, and to support practitioners adopting a whole family approach. A series of whole family workshops have also been designed to facilitate open dialogue around the caring relationships, the impact this may be having on the young carer and how the whole family can support one another. Finally, partners are delighted to conclude with the launch of an e-learning programme. This interactive programme aims to increase practitioners' knowledge and confidence in adopting a whole family approach to support young carers. It also presents good practice across Europe and an evaluation plan to successfully measure the impact of the Together resources.

The e-learning programme contents have been collected in this booklet in order to reach practitioners who are unfamiliar with the e-learning platform or prefer to have written support.

MODULE 1 – INTRODUCTION

Introduction

This course is for professionals and volunteers who are working with children, young people and families in youth or health and social care sectors.

There are many children and young people who provide unpaid care to family members in every society.

The aim of this module is to improve knowledge and awareness of *young carers* and the issues impacting these children and young people and their families.

In this course, we will also explore why taking a whole family approach to supporting young carers is important.



Definition of young carers

A young carer is someone under 18 who helps look after someone in their family, or a friend, who is ill, disabled, has a mental health condition or misuses drugs or alcohol.

Young people who are aged 16–25 and care, unpaid, for a family member or friend are known as young adult carers.

These children and young people take on additional tasks to support their family in everyday life. Young carers often have many responsibilities that most other children and young people do not have.

Young caring is individual and unique to each family situation. Young carers are likely to take on more household tasks such as preparing meals and cleaning, be responsible for grocery shopping, take their cared for person to medical appointments, or help to take care of other siblings. They may provide emotional support for their cared for person. Some young carers may also assist with personal care, such as helping to wash or dress the person they care or administer medication.

Young carers are children and young people first and foremost and should not be undertaking inappropriate caring roles.

Some data on prevalence

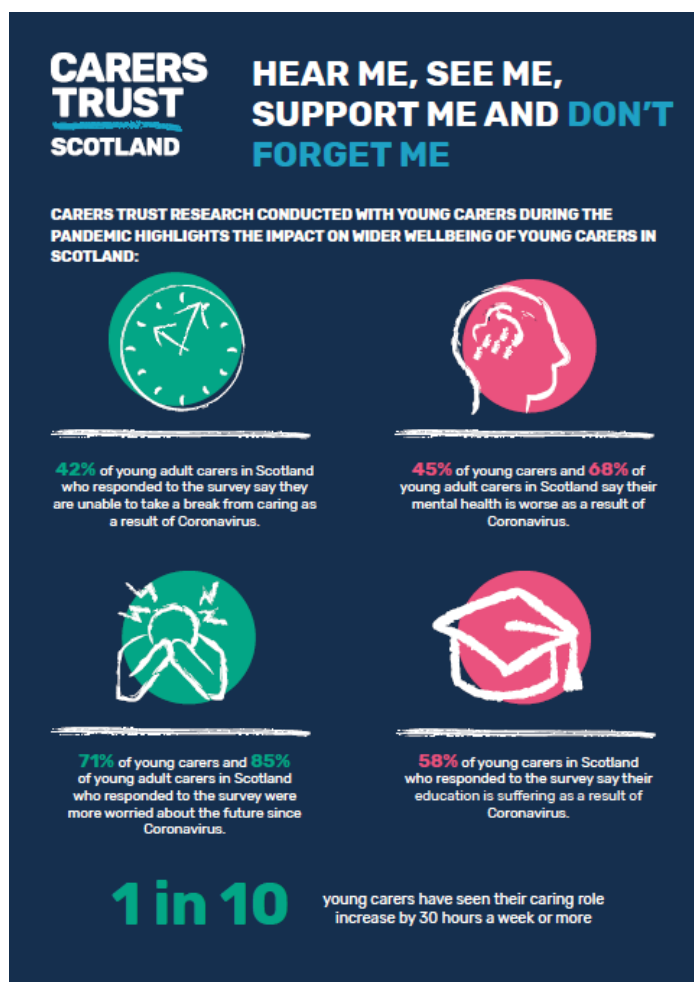
In Scotland there are an estimated 1.1 million unpaid carers. Overall 59% of unpaid carers are female and 41% are male in Scotland¹.

Scottish Government recognises that there are at least 29,000 young carers in Scotland,² but it is generally accepted that this is an underestimation. Some research and survey work estimates that there could be as many as 100,000 young carers in Scotland.

¹ Carers Strategic Policy Statement: Consult: <https://www.gov.scot/publications/carers-strategic-policy-statement-draft-consultation/###targetText=The%20Carers%20Strategic%20Policy%20Statement,support%20unpaid%20carers%20in%20Scotland>

² Scotland's Carers, Scottish Government (2015): <https://www.gov.scot/publications/scotlands-carers/>





Unpaid care in Scotland is estimated to be worth £10.8bn each year.³ Around 70% of unpaid carers receive no support with caring responsibilities.⁴ 47% of unpaid carers in the most deprived areas care for 35 hours a week or more in Scotland. Caring therefore may stem from a lack of choice and may be exacerbated by existing inequalities of incomes and poor health in these areas.⁵

³ Carers Strategic Policy Statement: Consult: <https://www.gov.scot/publications/carers-strategic-policy-statement-draft-consultation/###targetText=The%20Carers%20Strategic%20Policy%20Statement,support%20unpaid%20carers%20in%20Scotland>

⁴ Scottish Government (2015), Scotland's Carers: An Official Statistics Publication for Scotland (Scottish Government).

⁵ Scotland's Carers, Scottish Government (2015): <https://www.gov.scot/publications/scotlands-carers/>



Issues faced by young carers

Alongside school, training, or wider studies – as well as potentially employment for older young carers - young carers can take on significant responsibilities at home and to support their cared for person. Many young carers don't recognise their role as “unpaid caring” and instead view their role as the norm in their lives as a family member. Young carers often take on levels of responsibility that is not usually attributed to their age group.

Taking on these tasks and carrying this kind of responsibility becomes part of their everyday family life. However, young caring can significantly and sometimes negatively impact a child or young person's life. Young carers' education can suffer, as they may struggle to keep on top of their studies and caring may impact their attendance at school. Young carers may often be late for lessons or overtired because they have intense caring responsibilities at home. Many young carers report feeling isolated and they may not always be able to have the time to socialise with friends or to pursue hobbies. Most young carers will be living in households which partly or completely rely on social security benefits as the main income to the household. Financial worries can add barriers for young carers and further limit their ability to socialise with friends or to pursue hobbies. In addition, young carers may spend a lot of time worrying about their cared for person and wider family, which can impact on their mental health and wellbeing. They may find it difficult to switch off during their free time or to concentrate in class.

In 2021, a group of young carers, known as the Media Ambassadors, created their own film with Carers Trust Scotland to raise awareness of the impact caring roles can have on their lives. Their final film explores issues that matter most to them, including education, respite and loneliness. You can watch this [here](#).

When young carers want to move out of the family home, further problems arise. In providing unpaid care, young carers bridge a gap in care provision for the cared for person. This gap needs to then be filled by other family members, by statutory support or by the paid care workforce. Many young carers may struggle and delay moving out of the family home as they feel as though they are letting their cared for person down or because there are no obvious other options for alternative care provision. It is vital that young carers are able to progress in their own lives and are supported to stop caring if they choose to.

Besides the negative impact that an unpaid caring situation can have on young people, there are also positive aspects of unpaid caring that should not go unconsidered. Young carers can



develop skills in areas of empathy, social competence, sensitivity, and responsibility as a result of their caring role.⁶

The complexity of unpaid caring relationships at home can make it difficult for young carers and their families to seek help and support. Young carers need support to maintain positive health and wellbeing.

A whole family approach: what is it

An illness, condition or disability of a family member affects all other family members and can present new challenges. In order to deal with these challenges, it makes sense to involve all family members in finding solutions and restructuring everyday life.

Adopting a whole family approach involves practitioners supporting young carers in the context of their families. Identifying young carers' needs and considering the impact of caring responsibilities on the whole family, and what personalised support is required ensures that inappropriate caring does not take place. This holistic approach ensures that appropriate support is provided and promotes open dialogue within families about the caring relationship.

The whole family approach for families

Sometimes a care situation presents abruptly (for example, due as a recent diagnosis in the family) and sometimes it is a slow process (for example, a family member having a deteriorating condition such as Alzheimer's). The condition of the cared for person and each family structure will impact unpaid caring roles for individuals in the family. In addition to the new tasks related to supporting the cared for person, tasks that the cared for person used to be responsible for must be reallocated to other family members, or these tasks may not be able to be maintained. On top of the organisational aspects, there is also the worry about the cared for person, which can impact the mental health and wellbeing of all family members.

The preference of most families is to try and maintain as much normality for their family as possible. Internal family communication, the financial situation and societal aspects play an important role in how unpaid caring is dealt with in the family. The extent to which professional support (counselling, care services, paid carers etc.) is received can also have an influence on the family structure and the stability of this.

⁶ Nagl-Cupal et al. 2012, S.188 ff.



It is important to involve all family members in the organisation of the new everyday life so that the daily structure and the family togetherness can continue, and in order to be able to have open communication amongst the family members to help prevent issues arising.

A whole family approach: why is this relevant for young carers

If unpaid caring is recognised and understood through a whole family approach lens, then professionals have the opportunity to better support young carers and the wider family.

As discussed earlier, a major factor can be lack of communication within the family. Lack of communication in the family home may also be due to a lack of awareness and identification of young carers; resulting in many remaining hidden and unsupported. Many families may not recognise their children as 'young carers', some children and young people do not recognise or identify with the label, and there can be a degree of reluctance, even anxiety, among families in disclosing caring responsibilities. Adopting a whole family approach is therefore vital to ensuring that young carers and their families are identified, fully supported and empowered.

If families do not talk openly about the caring relationship, caring responsibilities may be taken on without any discussion of choice. If parents/guardians do not regularly talk to their children about their needs and give them the opportunity to speak openly about their feelings, this could negatively impact the health and wellbeing of the child or young person.

Encouraging open dialogue raises awareness with family members about the impact caring roles can have on young people's lives. It contributes to tackling stigma that some families still feel towards caring and the involvement of services in their lives. This approach also provides the information and advice families may need, empowering them to seek out the support that can help them. Ultimately, adopting this approach ensures that young carers are not taking on inappropriate caring responsibilities, allowing them to be able to live their own life alongside their caring role.

Professionals can support honest and open communication and signposting to wider external support. Open communication also enables young carers to be informed about their cared for person's condition and therefore may reduce worry or fears.

A whole family approach is therefore essential to help ensure that young carers and their families are recognised, fully supported, and empowered.

Additional resources

Video from Carers Trust, Pie- A Story for Young Carers



Video from Carers Trust Scotland, Media Ambassadors 2020: Scottish Young Carers Festival
Youth Team 2020: Carers Parliament Presentation - YouTube



MODULE 2: HOW TO MAKE USE OF THE IO1 RESOURCES

Introduction: What will we learn?

The objectives of this module are to:

- Introduce practitioners to the importance of awareness and self-identification of young carers.
- Summarise the process undertaken by the Together project partnership in creating awareness raising resources.
- Advise practitioners in using these resources effectively to support young carers using a whole family approach.

The importance of awareness and self-identification of young carers

Inappropriate caring has a huge impact on young carers' health and wellbeing. A substantial factor that can contribute to this is a lack of communication within the family. Where families do not openly talk about the caring relationship, caring responsibilities may be taken on without a discussion about free choice.

Lack of communication in the family home may be due to a lack of awareness and identification of young carers; resulting in many remaining hidden and unsupported. A significant proportion of young carers have not disclosed their caring responsibilities to their schools, they are no more likely to be in contact with social services than their peers, and only a minority have had an assessment of their needs or been informed about sources of help.⁷ Furthermore, many families may not recognise their children as 'carers', some children and young people do not recognise or identify with the label, and there can be a degree of reluctance, even anxiety, among families in disclosing caring responsibilities, particularly children and young people caring for a relative with drug or alcohol problems.⁸

The first phase of our Together project was therefore to address some of these challenges through the creation of awareness raising resources. Raising awareness and encouraging young carers to self-identify is vital to ensure that inappropriate caring does not take place. Our resources aim to raise awareness of young carers and the impact caring roles can have on a young person's life, as well as encouraging young people and their families to seek out the support that is available.

They also support a wide range of practitioners, who could be the first point of contact for these families such as GPs, teachers, mental health and drug and alcohol support services,

⁷ Dearden, C and Becker, S., 2004. Young carers in the UK: the 2004 report. London: Carers UK

⁸ James, E., BARNARDO'S, 2017. Still Hidden, Still Ignored: Who cares for young carers? Barnardos: Essex.



to adopt a whole family approach to ensure that young carers and their families are identified, fully supported and empowered.

Below you will find information on how we created these resources, what the response has been through our pilot and how you as a practitioner can use these when supporting young carers.

Creating our materials

The first part of our Together project involved a significant amount of desk-based research to find out what tools and resources are currently available to support young carers, families and practitioners using a whole family approach. This collection process defined the scope and limitations of existing materials and the gaps to be targeted through our Together project work. From this scoping exercise, partners collated the most appropriate resources into our project database. This database can be accessed on the project website and practitioners can filter depending on key word searches, target groups or country specific materials.

Consultation with young carers and practitioners also ensured meaningful resources would be created. This activity provided partners with a baseline knowledge of the whole family approach, and where gaps and challenges existed in each nation specific context. It was important that each partner created a set of resources appropriate for their nation's unpaid carer landscape and the level of awareness that existed. Each partner therefore developed individual resources for young carers, family members and practitioners.

Whilst resources were created for each partner's national context, the key messages remained the same. These resources remind young carers and their families that they are not alone. They aim to provide useful information and support for families, and to encourage them to speak openly with one another about the caring role.

For practitioners, these resources demonstrate that lasting positive change and support is more sustainable when working with the whole family.

Examples of resources

Partners created a variety of resources that reach out to the following groups:

- To young carers about the importance of understanding more about their family member's illness, discuss it in the family and find a supportive adult to talk to.

- To family members to help them understand how caring roles can impact a young person's life.
- To professionals working with young people to raise awareness and help them understand the impact of young caring and what they could do to support young carers using a whole family approach.

These resources have been well received as demonstrated through a pilot survey. Surveys included baseline questions to measure confidence and awareness of participants using a whole family approach and received over 100 responses from young carers, family members and practitioners. Pilot results indicate that the resources have helped to successfully increase knowledge, awareness and confidence in using a whole family approach. Based on this feedback, partners made appropriate edits, ensuring that the project resources are fit for purpose and will continue to be well received by young carers, family members and practitioners.

Final project resources include leaflets, bookmarks, posters, toolkits and interactive conversation cards. All resources are available on the project website www.togethereuproject.eu and can be downloaded.

Country specific approaches

Each partner has created their nation specific resources and suggestions in using these materials as a practitioner.

In Scotland, the following resources were developed, freely available on the project website:

- Conversation cards to support young carers and family members to discuss caring roles in an interactive way. These cards also include information and links to support families with caring responsibilities.
- A toolkit for practitioners providing practical steps, guidance and useful resources to adopt a whole family approach.
- A project poster to raise awareness of the whole family approach and the wider Together project.
- A bookmark for young carers to support self-identification and promote information and support available.

Conversation Cards

Caring within the family: starting that conversation, together.



Young carers involved in Carers Trust Scotland's national youth projects helped shape these resources to ensure they supported young carers and their families in the best way possible. Our conversation cards are made up of young carer and family cards. Each card has one discussion point on one side and prompts and information on the other. There is no right or wrong way to use these cards, they have been created to help families understand more about young caring and the impact it can have. They encourage family members to be open and honest and offer some questions to help families to start talking together.



They also include information and useful links to organisations and services to support families with caring roles in Scotland.

'Caring within the family: Starting the conversation, together.' Conversation

Young carers and family members can use these individually to reflect on key questions or use together to learn more about the impact caring is having on the individual. Practitioners can use these cards to individually support young carers to express how they are feeling. This resource also provides an introductory understanding of who young carers are and the impact caring can have to family members. When used in an interactive way, practitioners can support families to go through the cards and provide prompts or additional information on the links that are signposted. These cards can be used during whole family workshops or shared with families to take home and use in their own time.

Practitioner Toolkit

Due to the advanced carers' rights landscape in Scotland, it was important that our practitioner resource would complement the work that so many are already doing to support young carers, particularly young carer services. Despite this advanced policy landscape, desk-based research and consultation shed light on key challenges and barriers in adopting a whole family approach when supporting young carers.

In response to this, we created a practitioner toolkit that provides practical steps, guidance, examples and useful resources. The toolkit is designed to support and complement the work practitioners already do across Scotland in supporting young carers.

The toolkit provides a project background and highlights the importance of adopting a whole family approach. It includes practical steps for practitioners, including a brief guide to having difficult conversations. This section was included specifically based on consultation from youth services, who found that initiating conversations with families at times a difficult conversation to have. Due to the complexity of families and the variety of caring roles that exist, we also included resources that support different family structures and condition specific materials.

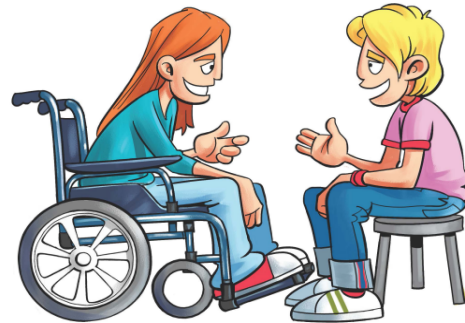
Information on Young Carer Statements and small steps that practitioners can include to adopt a whole family approach is also included, as are good practice examples from different local authorities in Scotland.

Consultation with young carer services also informed the final part of this toolkit. There was a need to record outcomes in one place to ensure greater communication across services. Therefore, the toolkit concludes with a personal outcomes approach and a family action plan that can be developed alongside a Young Carer Statement or during whole family workshops. Practitioners can use this action plan to take notes of issues, perspectives, and experiences of all individuals, and develop key actions to support the whole family. As resources must be flexible to adapt to different local authorities and their approach to supporting young carers, the plan is straightforward and can be used as a starting point for practitioners. Partnerships are so important and practitioners should ensure to link in with the local authority carers planning team to explore what wider support may be available for families.

Case Studies:

'This is an excellent resource not just for practitioners working with young carers and their family but for any professional to gain a better understanding of young carers and their family life.' Education Officer, Scotland.

Together: A Whole Family Approach for Young Carers



'They are very user friendly and easy to follow which makes structuring the conversations with the young people which will make it focused conversations.' Young Persons Practitioner, Scotland.

'Having discussed this with a colleague regarding a particular young carer's situation, we felt it would be useful in working with the child and the whole family, a different way of opening up what can be a difficult conversation. It could also be useful for colleagues to use in education in conversations about caring roles and referrals to carers support. We liked the visual appearance and thought this would appeal to children and young people.' Young Carers Manager, Scotland.

Testimonies:

'I have learnt how to better communicate with my family about the impact my caring role can have on my mental health.' Young carer, Scotland.

'It provides helpful advice on how to openly communicate with your family which I have found particularly helpful as I am someone who struggles with this. The design is a good way to keep the communication between carers and family members lighthearted and easy.' Young carer, Scotland.

MODULE 3 – HOW TO MAKE USE OF IO2 RESOURCES

1. Introduction

Module 3 is addressed to professionals and volunteers working in the youth sector. It aims to support practitioners to encourage positive communication and mutual support between young carers and family members. The final objective is to be able to deliver a series of interactive workshops for young carers and their families, which aim to support the creation of an open dialogue about the condition of the cared for person, the impact of caring on the young person and how the whole family can respond to this by helping relationship building within the family.

2. Core contents

Supporting young carers through a whole family approach: existing types of interventions and approaches

When there is a person in the family who needs care, whether due to being ill, disabled, having a mental health condition or misusing drugs or alcohol, the impact caring roles are having may not be discussed within the family. The Together workshop, addressed to both young carers and family members, promotes strong communication within the family and offers a safe space for sharing and promoting an open and honest dialogue.

The ultimate goal is to encourage young carers and their family members to share more about the cared for person's condition and the impact caring responsibilities can have. These workshops provide young carers the opportunity to discuss issues relevant to them and be listened to by their family members, thus reducing the negative impacts caring responsibilities can bring and improving young peoples' wellbeing, social inclusion and community engagement.

The Together intervention model:

Concept of the model / description of the methodology

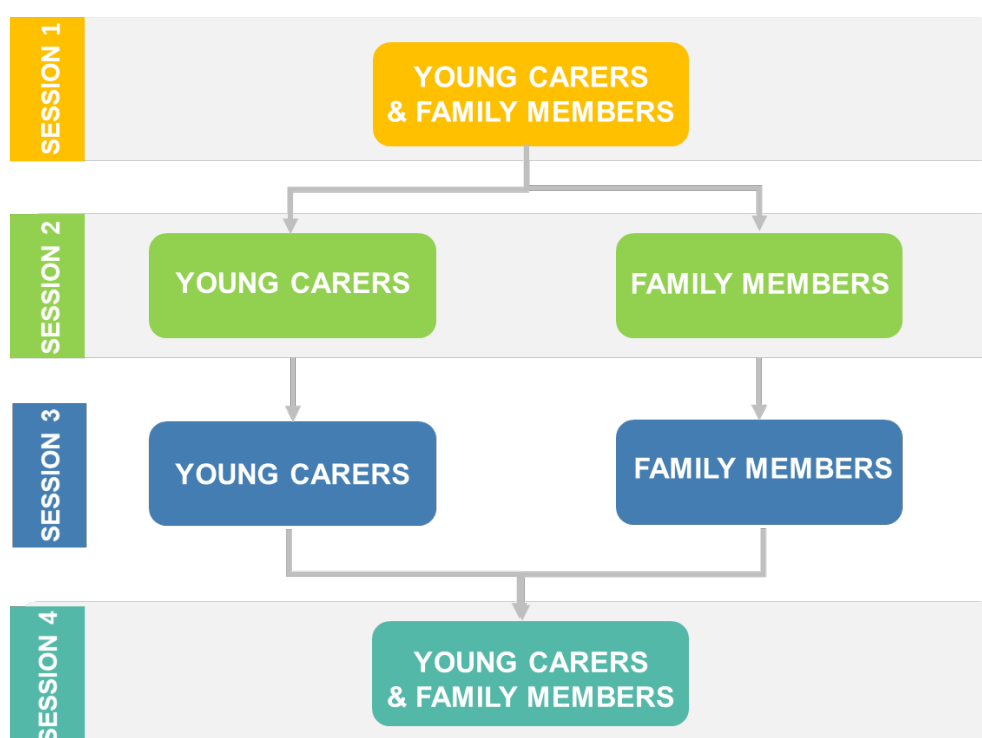
The Together model aims to implement a programme that, through practical activities, stimulates reflection and facilitates the sharing of feelings, experiences and perceptions of caring roles within the family.

It is designed to involve at least ten participants (five young carers aged 13-25 and five family members) and all family members, including the cared for person can be invited to participate in the workshop. However, the participation of all family members is not mandatory, and it is



important to consider that not all carers may want to participate in the workshop. The workshop is addressed to all young carers and their families regardless of the caring situation.

The workshops are divided into four weekly sessions, for a total of six meetings, of about 90 minutes each. In the first and last session young carers and their families are together, while in the remaining two sessions they are separated into two different groups.



All sessions keep the same structure: icebreakers, core activities and final activities. When participants are separated into groups, they engage in the same activities and then feed back to the whole group.

As the content within these sessions covers emotional topics and personal experiences, all the activities proposed are interactive and engaging, such as exercises and games. When developing these sessions, partners considered existing tools for youth and adult education, awareness-raising measures from different care contexts and family communication models. This ensured we could build on good practice models, including the existing knowledge and experience of the project partners.

In order to monitor the impact of the workshops, a questionnaire can be submitted before and after each session in order to measure the effectiveness of the workshop and the impact on participants.

Objectives of the intervention

The workshops are designed to be divided into four sessions, each with specific topics, objectives, and practical activities. The four sessions deal with different but consequential topics, as follows:

SESSION 1 - “Our needs”: This session aims to provide an overview of the topic of young carers. Introductory activities aim to support participants and raise their awareness of their own needs and those of family members, as well as the emotions attached to this.

SESSION 2 - “Our emotions”: The second session aims to increase self-awareness, supporting participants to become aware of their emotions related to caring activities, and share these with the group.

SESSION 3 - “Our communication”: This session aims for participants to become aware of and reflect on one's own communication style as well as that of the family, to be able to communicate one's feelings and thoughts and to practice active listening. The session ends with the Question Box activity that gives participants the chance to share questions to young carers/family members.

SESSION 4 - “Out path together”: This concluding session aims to summarise what has emerged during the course, including the possible similarities and differences between the target groups during their individual sessions. The specific aims of this session are to become aware of the emotions and thoughts of others in relation to caring, to facilitate communication between family members and to provide a safe space to talk about caring activities (and related emotions) within the family.

Each session includes an introductory activity to recap on where the previous session left off and a concluding activity in which facilitators recall what was done during the session and what emerged.

Suggestions for implementation

The workshop should be led by two experienced facilitators who regularly work with young carers and their families. Facilitators can be educators, social workers, youth workers and/or psychologists. It is possible, but not mandatory, to involve a third facilitator who can help to deal with difficult situations, for example if a participant shows discomfort and needs to speak to a facilitator individually. It would be ideal for the workshop to be held in person but the proposed activities, with small adjustments, can also be delivered online.

The number of workshops and the duration of each activity can be changed and adapted.

After developing the Together model, each partner country made small modifications to adapt the workshop to the context and situation of their country. From the pilot, the following suggestions have been collected from the different partner organisations:

Italy:

- It would be useful to deliver the workshop to younger children after making the necessary modifications and adaptations. Allowing younger children to practice open communication from an early age would help to sustain a positive relationship with their family members.
- It is important to design the workshop structure by considering potential barriers to family members' participation, for example lack of time or anxiety around disclosing personal and emotional experiences.

Scotland:

- To fully support the participation of families, the number of sessions delivered can be reduced. Facilitators should be aware of the amount of time families can commit to the workshops and if appropriate, can combine some of the activities or implement the most relevant and effective. During Scotland's pilot, defining young carers and providing the tools to self-identify was considered unnecessary because families working with young carer services already had a clear understanding of who young carers are and the local services supporting them. Facilitators are therefore able to be flexible and adapt to the needs of participants.
- Literacy levels of participants should also be considered when running certain activities such as the Blackout Poetry. Facilitators must ensure that texts used are jargon-free and easily accessible.
- Accessibility requirements should also be discussed and considered in the planning of the workshop and resources.
- It is recommended that these workshops are delivered to families with similar caring roles. This would ensure all attendees feel comfortable discussing caring relationships and could benefit from peer support.

Greece:

- The contents and activities delivered must be suitable for a wide range of ages.
- Young carers in some cases, due to their lack of participation in similar seminars in the past, might need more time to feel comfortable and be able to express their personal opinions and feelings about caring. While family members, due to their greater involvement in patient care, may go beyond the scope of the discussion. The facilitator must ensure to bring the focus back to the workshop objectives.



Germany:

- It would be useful to reverse session 1 on needs with session 2 on emotions, because it might be easier to explore within oneself and one's emotions first and then reason about one's needs.
- It is suggested that the workshops are given greater time and facilitators emphasise that young carers are at the centre of this experience.

The full programme including all four session plans, resources, pilot results and advice to implement both online and in presence is available for free download on the project [website](#).

3. Case Study

Young carer services in Scotland provide direct face to face support to young carers. This can include young carer groups, one to one support and providing local information and advice. Young carer services support young carers in several ways including raising awareness of who young carers are and the local support available, liaising with schools to ensure appropriate support is put in place, and hosting young carer groups where young people can have a break from their caring role and make new friends with young people who understand what it's like to be a young carer.

The Together workshops are a great tool for young carer services as it ensures that greater links can be made with families and ultimately, young carers feel supported with their caring roles. These workshops provide a safe space for young carers to learn more about the condition or illness of their cared for person; information that some services are already providing through newsletters or one to one sessions. Therefore, implementing whole family workshops develops this work further and provides the information in a safe way. Furthermore, the pilot of these workshops has demonstrated how beneficial this can be for family members, who may otherwise not have the opportunity to engage with their peers. Services may implement these workshops to facilitate initial discussions with families about who young carers are, the impact caring roles can have and what local support is available. These can be difficult conversations for practitioners to have with families and thus implementing workshops ensures this can be achieved in an interactive way with peer support.

When running the workshops, it is suggested that young carer services invite no more than five young carers and their five family members to participate. This ensures that all attendees can participate fully. Services could implement these workshops to young carers and families who are new to the service, or to young carers who have identified a need for greater communication with their families through one-to-one sessions or in their Young Carer Statement.

Our Together pilot has demonstrated that these workshops can be delivered online or face to face. If delivering online, young carer services should take into consideration that each participant will need access to their own device to ensure everyone can participate in break out rooms. If this is not possible, sessions two and three must be held separately. Greater

time spent on introductory activities and ice breakers in session one will be needed if families are new to their young carers service or have never engaged with one another. Engagement online can be challenging, particularly as the workshops explore personal experiences that can be emotional. Allowing participants time to get to know one another will ensure everyone feels comfortable and safe to share their stories with the group and ultimately, get the most out of the workshop.

When delivering the workshops face to face, facilitators should consider that some activities and follow up discussions may run over their allocated time as engagement in person can be much higher. Young carer services should allow for some flexibility when delivering the activities and be guided by participants as to what activities spark the most discussion relevant to the workshop outcomes.

One final consideration should be the families who are invited to participate in these workshops. During our pilot, we discovered that families with similar caring roles were able to form a greater connection and share their experiences. These workshops offer peer support for young carers and their families and could also allow for certain activities to explore specific conditions or illnesses, if appropriate.

Overall, implementing the Together model complements the work that young carer services are already doing across Scotland. The workshops ensure practitioners can adopt a holistic approach in supporting young carers, as well as creating stronger links with families.

4. Testimony from a facilitator

Please see below a testimony from Allison, Young Carer Coordinator at Y Sort-It Young Carers Service in West Dunbartonshire about delivering the Together workshops and the impact this has had.

“The workshop went really well. The family feedback has been excellent, they have gained so much from it. They loved coming together, especially the parents who thought it was nice to speak to each other about the concerns they have, the worries and maybe even some of the guilt about their children being young carers. It was nice to have them together.”

“The workshops are definitely something we will use going forward, we are quite keen to do more work with families.”

MODULE 4 – HOW TO EVALUATE THE IMPACT

Introduction

Module 4 demonstrates the importance of evaluation and provides suggested tools to achieve this. This module is addressed to professionals working with young people and their families and aims to support the evaluation of whole family approaches.

Evaluation: a background

Evaluation means systematically collecting, analysing and interpreting information.

In essence, the evaluation should answer the following questions:

- What is the nature and extent of the problem?
- What approaches can address the problem?
- What is the target group?
- Does this approach truly reach the target group?
- Is this approach effective?

The answers to these questions are necessary in order to measure the impact of any work carried out in supporting young carers and their families. These results provide a greater understanding of the approaches taken and their quality. They are also important as they provide evidence-based reporting to policymakers and funding agencies.

Evaluations include both the implementation of the workshops and its impact on the participants. It should describe how and to what extent the workshop was implemented, if its design was successful and the impact this has had on the target group.

During the planning of the evaluation, decisions must be made on the variables and the indicators to be measured. Therefore, in answering the questions below, you should state what was measured, how and when.

- a. Which variables and indicators can offer useful information on how the workshops were implemented? What kind of information (qualitative or quantitative) do you need to evaluate the procedure?
- b. What methods and "tools" are you going to use? (interviews, questionnaires, observation)
- c. Where, when and how often will the data be collected?
- d. Who will be involved in the evaluation?
- e. How do you intend to analyse the data?



Practitioners should ensure an accurate description of the implementation and its development is included. This ensures that you can measure whether the workshops were implemented in accordance with their original design.

You should also find out if the intervention has reached the target group. You should answer the questions below and provide information on the number of participants, their age and gender, education and other relevant variables.

- a. How many people were involved in the intervention?
- b. What were the socio-demographic characteristics of the individuals approached?
- c. How did you gather this information?

The importance of evaluating

Evaluations measure whether an intervention has successfully achieved its goals or not. It is also essential to ensure that limited resources are utilized most efficiently for the greatest possible impact. During the implementation phase, the evaluation seeks to understand how the initiative is taking shape. At the end of a project, the evaluation assesses the extent to which project aims were met and identifies circumstances that led to both high and low levels of success. Additionally, evaluation also probes throughout for potential unintended consequences.

Evaluation is also really helpful in order to improve the approach taken. The results benefit the immediate project as well as enhance future initiatives with lessons learned. Finally, every opinion matters during an evaluation. Participants' feedback highlights areas of traction and areas that warrant further attention.

Last but not least, it is crucial that the impact of an intervention is measured. This is important because it can improve the approach taken or inform decisions about whether to continue, discontinue or duplicate activity. The impact evaluations can also be used formatively if an intervention is ongoing. For example, the findings of an impact evaluation can be used to improve implementation of a programme for the next intake of participants by identifying critical elements to monitor and tightly manage.



Evaluation tools used in Together: concept and suggestions for use

Evaluations should examine how the participants feel about the workshops and what impact it has had on them. The suggested tool presented below includes quantitative and qualitative questions. These focus on the following thematics:

- The respondent's rating of his/her participation in the programme.
- The participants' satisfaction.
- The relevance of the programme.
- The skills and knowledge gained from the programme.

Participation				
1. Have you participated in a similar programme before?	Yes		No	
2. Was it easy or difficult to participate in the programme? Why?				
3 How would you rate your participation in the programme?	Excellent	Good	Average	Poor
Satisfaction with the programme				
1. The programme was satisfactory.	Yes		No	
2. Please explain your answer.				

Relevance of the programme				
1.The programme has met my needs.	Yes	No		
2 The programme is appropriate for people in similar circumstances to me.	Yes	No		
Skills and knowledge gained				
1.I gained useful skills and knowledge in the programme.	Strongly Disagree	Disagree	Agree	Strongly agree
2.I am able to apply the skills and knowledge gained in the programme in my daily life.	Strongly Disagree	Disagree	Agree	Strongly agree
3.Please explain your answer.				
Other Comments				
Please tell us any other thoughts or feelings you have about the programme. This will help us to improve going forward.				

References

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- <https://www.nichq.org/insight/5-reasons-why-evaluation-matters-your-project>
- <http://www.peri.net.ni/eValued/tutorial/importance.htm>
- https://www.betterevaluation.org/en/themes/impact_evaluation



MODULE 5: BEST PRACTICES

Introduction

This module presents good practice that exists across Europe to address the needs of young carers. It aims to provide practitioners with a better understanding of what makes practice successful, and the tools required to devise their own strategies to support young carers and their families.

As well as practical examples, this module outlines the benefits of co-production and the added value of international collaboration and knowledge exchanges.

Core contents

- What is a best / promising practice?

In the context of the Together project, best practice is defined as an initiative (e.g., a project, process, technique), which:

- Addresses the needs of young carers through a holistic, whole family approach. This means supporting young carers in the context of their whole family. Projects that identify young carers' needs and consider the impact of caring responsibilities on the whole family and what personalised support is required to ensure that inappropriate caring does not take place.
- Has been co-designed. Collaborating with young carers, family members and practitioners when designing projects or activities ensures that it will meet the needs of participants and be well received when delivered;
- Has already proven successful; and
- Has the potential to be applied in other geographic areas.

- The importance of learning from others

Across Europe, a substantial number of children and young people provide care to a family member or a friend who has an illness, disability, a mental health condition or addiction. While unpaid care is slowly gaining momentum on policy agendas across Europe, the situation and needs of young carers remain by and large invisible to the public eye. Yet, the failure to identify and support these children and young people comes at a cost and the impact of caring on carers' health and wellbeing, educational experience, employability and social inclusion is well documented.

Despite the relevance of young caring, many key stakeholders whose work has an impact on the daily life of young carers are often unaware or have limited knowledge about young carers and of the challenges faced by them. As a result, many young carers remain invisible and their needs for support are not met.



The reasons why children become unpaid carers are manifold and include (among others) the cultural background, a sense of duty, the lack of alternative options, love and empathy for the cared for person and a lack of financial and practical resources within families.⁹ Yet, research has shown that young carers in different countries and circumstances carry out broadly similar tasks - including support with basic activities of daily living (personal care) and/or instrumental activities of daily living (e.g. shopping, cooking, financial management);¹⁰ emotional support and supervision; managing the family budget and collecting prescriptions; helping to give medicine; or helping someone communicate.¹¹ Although data is incomplete, it is estimated that at least 7-8% of children in Europe – i.e. about 7 million children¹² - have caring responsibilities.

European countries may be at different stages when it comes to the awareness of young carers but it is clear that young carers across Europe present similar characteristics and that the challenges they face are also common across countries. As a result, it makes good sense to identify and disseminate successful practices which all practitioners can learn from. Sharing good practice can provide peer support and inspire practitioners when designing new projects or activities.

- *Types of interventions across Europe and their characteristics*

There are existing projects that include successful elements of a whole family approach. These projects provide a great starting point for practitioners to reflect on good practice as they develop whole family approaches to support young carers. Below you will find examples of these projects, including those which strengthen communication between adults and young people, supporting the self-identification of young carers, promoting the rights of young carers, providing youth friendly information on a specific condition or providing professionals with the tools they need to support young carers.

Initiatives rooted in the whole-family approach

The **KidsTime programme** launched in October 2020 by the Mental Health Foundation, in partnership with the charity Our Time and the London Borough of Southwark, aims to help families affected by a mental health condition.

⁹ Joseph, S., Sempik, J., Leu, A. and Becker, S. 2020. Young Carers Research, Practice and Policy: An Overview and Critical Perspective on Possible Future Directions, *Adolescent Research Review* 5, 77–89.

¹⁰ ADLs: Activities of Daily Living are self-care activities that a person must perform every day such as bathing, dressing, eating, getting in and out of bed or a chair, moving around, using the toilet, and controlling bladder and bowel functions. IADLs: Instrumental activities of daily living are activities related to independent living and include preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone.

¹¹ Joseph, et al. 2020, op cit

¹² Combating child poverty: an issue of fundamental rights, Fundamental Rights Agency, 2018



This programme is designed to support families where parents have a diagnosed mental health condition. It delivers group workshops which provide a fun, safe environment where families can come together to form a community, learn about mental health and support each other. The workshops are attended by parents and their children together for the whole family to learn about mental health and mental health conditions, facilitated by a small team who have been trained by Our Time. The workshops are designed to improve communication between parents and children and to increase the children's self-confidence using creative methods, including drama and discussion, to increase understanding about mental health and to safely explore feelings and experiences. At the end of each session, families enjoy a meal together to relax and promote connection. This project is part of the Mental Health Foundation's aim of preventing mental health problems before they develop and reach crisis point.

The **"SupaKids" project**, launched in Hamburg (Germany) in 2009 with the support of DRK Schwesternschaft Hamburg eV, sought to offer a first point of contact for children and young carers living with chronically-ill parents. Given the effects of a chronic illness and long-term care on almost all areas of a family's life, SupaKids consisted of various modules targeted at both children and parents. Some of these gave children and young people an opportunity to exchange ideas, relax and play together while others consist of a parents' café, a telephone hotline, opportunities to have a chat, access information on an illness or take a child-friendly first aid course.

Although closed in 2015, the SupaKids project proved very fruitful since parents and children visibly benefited from it, seeing it as a place of shelter where they could be themselves and find friends with similar experiences.

Initiatives aiming to strengthen the communication between adults (including the cared for person) and children/young people(young carers)

The effective Child and Family Intervention – Let's talk family intervention

This Finnish programme is targeted at families in which one or both parents have mental health or addiction problems, or other illnesses (e.g., cancer). It consists of a series of six to eight sessions (depending on the needs and number of children) in which parents reflect on the ways the illness has affected their families everyday life and how to support their child's wellbeing. The programme also includes a child session as well as a family meeting. The objective is to improve family relationships and communication as well as assist parents in building on the family's strengths to enhance their own and their children's resilience.

Initiatives aiming to support the (self-)identification of young carers



Childline is a free, private and confidential hotline provided by the National Society for the Prevention of Cruelty to Children (NSPCC) offering help and advice to anyone under 19 in the UK with any issue they're going through. In addition to a phone line, it is also possible to talk to a counsellor online, send Childline an email or post on the message boards.

The Childline website includes a page dedicated to young carers, which provides general information about self-identification as a carer, common challenges facing young carers, overcoming stigma and bullying, coping with stress and available support.

Storia di Marco, un giovane caregiver / story of Marco, a young carer is a video produced by Anziani e Non Solo (Carpi, Italy) in order to raise awareness of unpaid caring and encourage young carers to self-identify as such. The video was developed as part of the Erasmus+ funded project EPYC - Empowering Professionals to support Young Carers.

The video is accompanied by a dedicated website "Giovani Caregiver" - <http://www.giovanicaregiver.it/> which is targeted at young carers themselves and provides them with information about what it means to be a carer as well as advice on how to cope with stress and balance caring roles with school and social life.

Initiatives aiming to promote the rights of young carers and support measures available to them

The publication section of the Scottish government's website includes a charter which aims to help carers understand their rights under the Carers (Scotland) Act 2016. The charter provides details about the meaning of both an adult and young carer under the Act, available adult carer support plans, young carers' right to a Young Carer Statement (i.e. an assessment by local authorities of their circumstances and caring role), available support as a carer, Carers' right to be involved in services and in the hospital discharge process.

Initiatives aiming to provide young carers with child-friendly information about a specific illness or condition.

Mamma Uovo. La Malattia spiegata a mio figlio / Mother Egg. The disease explained to my son is a cartoon developed by the UOSC of Oncological Haematology, National Cancer Institute IRCCS, G. Pascale Foundation (Naples, Italy) which aims to help parents who face a haematological or oncological disease in the arduous task of talking to children about cancer and chemotherapy (with particular attention to side effects). Two comic books are also available: one from 2015, "Mamma Uovo, the disease explained to my son" and the other from 2018, "Papa egg".

'For family and friends – when someone close to you has MS' is a booklet developed by the MS Society in the UK that looks at the issues for partners, family members and friends of people who've had a diagnosis of Multiple Sclerosis (MS). The booklet includes information on:

- common questions and worries
- what to say when someone has MS
- information for couples and people with children
- issues for carers
- current treatments for MS
- where to get support

The booklet is illustrated with pictures and quotes from people with MS and their loved ones.

Initiatives aiming to equip care professionals with the information they need to identify and support young carers

See me, hear me, talk to me is a guide, developed by the Lewisham Council in the UK, explains how care professionals working with children, young people, and their families can help to recognise young carers and support their needs. It is based on the idea that it is everybody's responsibility to identify and support young carers and their families. Even if their professional role centres on working with adults, they are in a prime position to identify that a young person may have additional needs as a result of their parent's illness or disability, and to make sure they do not remain unnoticed.

An online database freely available on the project website has been developed as part of the Together project in order to showcase best practice across Europe to address the needs of young carers. These practices are either relevant to or rooted in the whole-family approach.

Additional resources

Carers Trust Scotland: Digital Education Hub

Carers Trust Scotland's Digital Education Hub demonstrates great practice across Scotland in supporting young carers. This hub is broken down by local authority, where practitioners can explore a variety of resources by young carer services to help identify and support young carers in school. Resources include awareness raising posters and leaflets, Young Carer Referral forms, school resource packs including lesson plans and Young Carer Statements. This hub provides a platform for practitioners to learn from others, find inspiration and reflect on their own approaches to supporting young carers in school.



Scottish Young Carers Services Alliance

The Scottish Young Carers Services Alliance provides opportunity for knowledge exchanges and peer support to practitioners. The Scottish Young Carers Services Alliance, hosted by Carers Trust Scotland, is a network of young carer services across Scotland and one of the National Carer Organisations. Members provide direct face to face support to young carers, and the network meets quarterly to discuss examples of good practice for young carers, national pieces of work and policy development. It hosts Education and Young Adult Carer themed subgroups and guest speakers are also welcomed from other organisations to discuss how they can work collaboratively with young carer services. The Scottish Young Carers Service Alliance provides practitioners with a safe and welcoming space to access peer support, share knowledge and practice, access information and training opportunities and be supported to implement local and national strategies concerning young carers.



