



**Toolkit for those affected by
someone else's co-occurring
mental ill-health and
substance use conditions
(Dual Diagnosis)**

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Introduction

This toolkit has been produced by Adfam to support loved ones of those who are having difficulties with mental health and substance use. Whether you've just found out that your loved one uses drugs or alcohol and has mental health problems, or have been supporting them for many years, getting the support that you need can be challenging.

This toolkit contains suggestions and resources for anyone affected by someone else's co-occurring conditions. Much of the information in this toolkit is drawn from guidance from professionals, including those working to support families on a daily basis. However, it is not intended as a substitute for professional or peer support where this would be beneficial, and we would urge you to seek additional help and support. You will find a directory of local family support services at <https://adfam.org.uk/help-for-families/finding-support/search-for-local-support>

Details of mental illnesses, descriptions of drugs and their effects, and treatment options are outside the scope of this toolkit. Further information can be found on the NHS website or at www.talktofrank.com

What are co-occurring mental ill- health and substance use conditions (dual diagnosis)?



Dual diagnosis is often not diagnosed... That is, it's complicated, under diagnosed, difficult to diagnose. People don't fit into 'nice' categories. One problem magnified another- e.g. a mental illness will make an addiction worse and vice versa.

Family member

Co-occurring mental ill- health and alcohol and/or drug use conditions refers to a broad spectrum of experiences. It is often also called 'dual diagnosis'. Dual diagnosis originally referred to

*"Adults and young people who have a clinical diagnosis of psychosis with coexisting substance use"*¹

National Institute of Clinical Excellence (NICE) guidelines

However, in practice, the term is often used much more broadly than this to encompass a range of mental health problems alongside substance use. We are using the term 'co-occurring mental ill- health and substance use conditions' as it more accurately describes the experiences of families we have spoken to. Often the loved ones of families we speak to may not have received official diagnoses, and often they are struggling with complex health needs – not just a 'dual' problem. However, we recognise that 'dual diagnosis' is a common shorthand. Where it is used in this toolkit it can be seen as synonymous with 'co-occurring mental ill- health and substance use conditions'.

We use these phrases to mean:

"Any individual (adolescent or adult) who is experiencing mental ill-health and is using alcohol or illicit drugs or misusing prescription medicines to the extent that it is impacting on their wellbeing"

For ease of use, and in line with Public Health England's guide for commissioners², we have shortened this to '**co-occurring conditions**'.

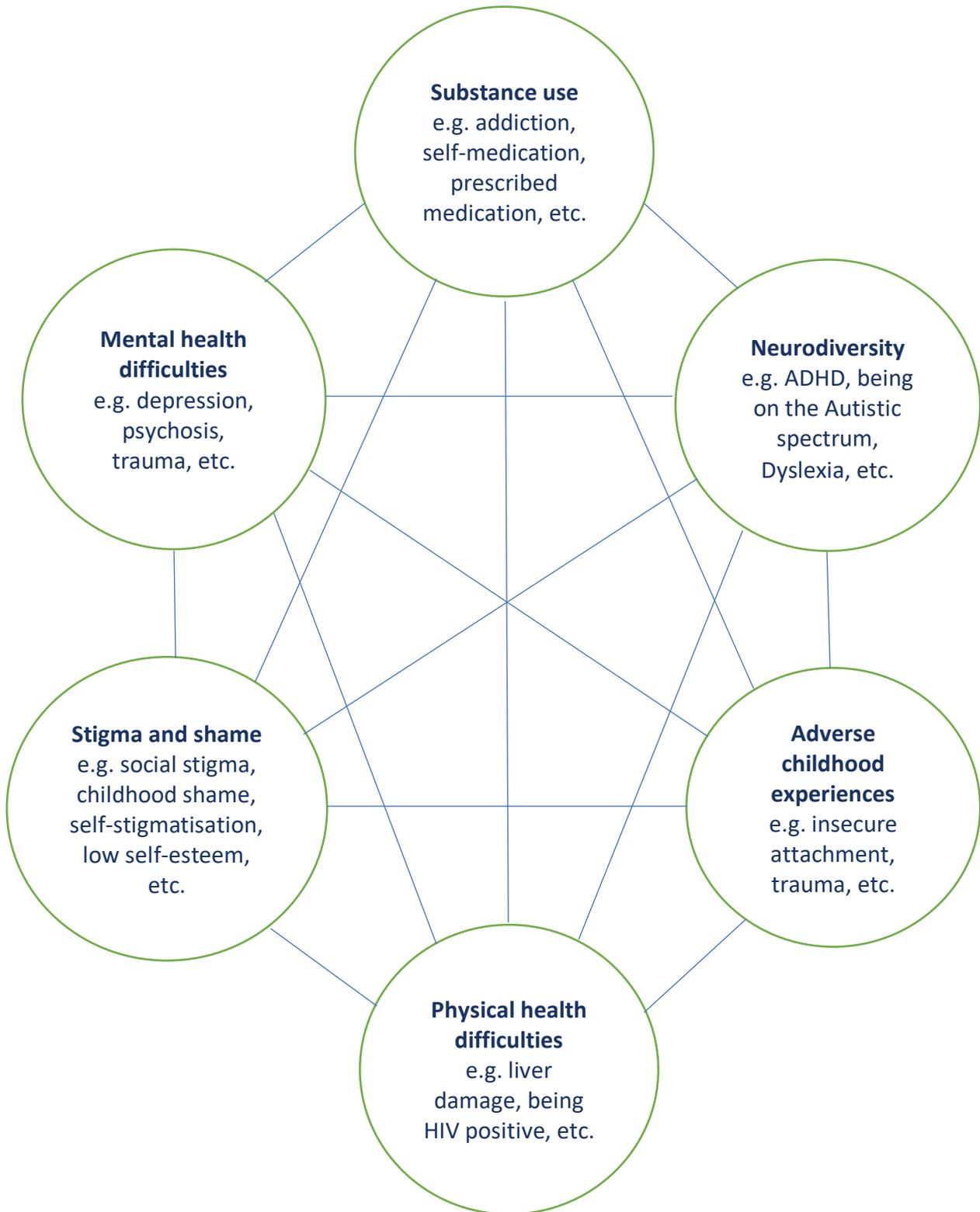
This toolkit is aimed at family members of those with co-occurring conditions. For the person themselves, there is lots of helpful information about the services that can help on the Mind website: <https://www.mind.org.uk/information-support/types-of-mental-health-problems/drugs-recreational-drugs-alcohol/dual-diagnosis/>

¹ Coexisting severe mental illness (psychosis) and substance misuse: assessment and management in healthcare settings, NICE guideline, 2011

² Better care for people with co-occurring mental health and alcohol/drug use conditions. A guide for commissioners and service providers; Public Health England, 2017.

The potential experiences of someone with co-occurring conditions

Each experience can be redefined as a need that treatment, counselling, and support can help with.



Source: Peter Cartwright

Substance use and mental health

Although both mental illness and substance use can occur in isolation, it is very common to find that someone is affected by both. Around one in three people with an enduring mental health problem also has a substance use problem. The relationship between the two can be complicated. It may be impossible to determine whether substance use has caused, triggered or made a mental health problem worse, or whether a mental health problem has led to substance use. For example, someone with anxiety may take drugs because it helps them feel calmer. This is known as 'self-medicating'. Someone else may experience increased anxiety or other mental health challenges as a result of drug use.

Co-occurring conditions may also differ in their severity. It's possible to have a serious, chronic mental health problem and substance use that is not dependent but is impacting on the person's (mental) health; or someone may be dependent on a substance alongside a mental health issue that is not considered to be serious enough to warrant a diagnosis. Many individuals have also never had a full assessment or sufficient contact with services to receive a diagnosis.

Both mental health and drug use can fluctuate over time, so people with co-occurring conditions may have good and bad days; stable and less stable periods; times when they are using substances heavily and times when they feel well.

It can be particularly hard for people with co-occurring conditions to access and engage in treatment, either because of the symptoms of their illness or because services are not able to meet their multiple needs. In addition, they and their families often face stigma and discrimination. Fortunately, there is increased awareness in society of mental health problems and the association with substance use. In recent years, national guidance on best practice in supporting patients and their families has been published and the key points are outlined below.

National Guidance



Relatives often know more than is thought about causes and could help in the recovery if considered for interview

Family member

Several pieces of guidance have been produced in the last few years and it can be difficult to understand what is relevant. Some of the main points regarding families of people with co-occurring conditions are outlined below. We have highlighted the sections that relate specifically to families.

Findings.org.uk have summarised the key legislation and you will find links to their summaries below, from which the extracts are taken.

Psychosis with coexisting substance misuse: assessment and management in adults and young people.

This guideline covers the assessment and management of people aged 14 and older with a clinical diagnosis of psychosis plus coexisting substance misuse. It aims to help healthcare professionals guide these people to stabilise, reduce or stop their substance misuse, to improve treatment adherence and outcomes, and to enhance their lives.

People with psychosis and coexisting substance misuse should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals.

If the person agrees, families and carers should have the opportunity to be involved in decisions about treatment and care. Families and carers should also be given the information and support they need.

When working with adults and young people with known or suspected psychosis and coexisting substance misuse, take time to engage the person from the start, and build a respectful, trusting, non-judgemental relationship in an atmosphere of hope and optimism.

For most adults with psychosis and coexisting substance misuse, treatment for both conditions should be provided by healthcare professionals in secondary care³ mental health services such as community-based mental health teams.

https://findings.org.uk/PHP/dl.php?f=NICE_120.txt&s=eb&sf=rel

³ **Secondary care** is NHS services which generally require a referral from a GP. Examples of secondary mental health services are hospitals, some psychological wellbeing services, community mental health teams (CMHTs), crisis resolution and home treatment teams (CRHTs), assertive outreach teams and early intervention teams. This differs from **primary care**, which is often the first point of contact for people in need of healthcare. Primary care describes professionals such as GPs, dentists and pharmacists. Drug and alcohol services, whilst sometimes provided by the NHS, do not sit within this tiered system. Someone can self-refer to a drug and alcohol service, or be referred by a GP or another service.

Coexisting severe mental illness and substance misuse: community health and social care services.

At first contact with services, aim to meet these service user's immediate needs, wherever they present. This includes looking out for multiple needs (including physical health problems, homelessness or unstable housing) and remembering that stigma may make it difficult for them to access services.

Provide direct help, or get help from other services, for any urgent physical health, social care, housing or other needs, and **ensure their safeguarding needs and those of their carers and wider family are met**. Ensure that the focal patient is referred to and followed up within secondary care. Mental health services should take the lead in assessment and care planning.

Mental health services should adopt a person-centred approach to reduce stigma, address any inequity in access to services, and undertake a comprehensive assessment of the person's mental health and substance misuse needs.

On the patient's acceptance at a secondary care mental health service, provide a care coordinator working in mental health services in the community to act as a contact for the patient, **identify and contact their family or carers**, and help develop a care plan with the patient and coordinate it.

Care plans should also take into account the concerns of the patient's family or carers... If they agree, share a copy of the care plan with the patient's family or carers and (in line with local information-sharing agreements) with other services as needed.

Mental health services should ensure carers are offered an assessment of their own needs. Based on this assessment, advise the carer that they may be entitled to their own support, for example, using a personal budget to buy care or to have a break from their caring responsibilities. Give information and advice on how to access services in the community, for example, respite or recreational activities or other support to improve their wellbeing.

https://findings.org.uk/PHP/dl.php?f=NICE_58.txt&s=eb&sf=rel

Better care for people with co-occurring mental ill- health and alcohol/drug use conditions: a guide for commissioners and service providers⁴.

Everyone's job. Co-occurring conditions are the norm rather than the exception, and commissioners and providers of mental health and alcohol and drug use services have a joint responsibility to work collaboratively to meet the needs of people with co-occurring conditions.

No wrong door. Providers should have an open door policy for people with co-occurring conditions, supported by commissioners that enable services to respond collaboratively,

⁴ People with co-occurring conditions: commission and provide services, 2017:

<https://www.gov.uk/government/publications/people-with-co-occurring-conditions-commission-and-provide-services>

effectively and flexibly to presenting needs, offering compassionate and non-judgemental care centred around the person's needs, accessible from every access point.

Collaborative delivery of care. Care may be provided by the same person or by relevant practitioners/services working in close collaboration. This requires accountability and clarity of role, information-sharing agreements, and shared care planning, with the individual at the centre of the process.

Care that supports and involves carers and family members Carers have needs in their own right. As part of delivering timely, compassionate and effective care to people with co-occurring problems, practitioners should identify carers and family members who may have unmet needs, making appropriate referrals for carers' assessments and/or to family support services. This may include: considering the impact of caring on their mental and physical health; that carers may not be aware of or included in any plans or decisions made by the person; the extent to which the carer can/will meet the person's support needs; and the need to create support networks.

Therapeutic optimism. Practitioners should demonstrate a genuine belief in the possibility of recovery, and all interaction and engagement with people using services should be undertaken in a spirit of optimism, with a clear commitment to helping them achieve recovery.

Episodes of intoxication are safely managed. People can be at risk of harm to self and/or others when experiencing a mental health crisis, and the risks are heightened if they are intoxicated. Services need to ensure that they are equipped to respond, which means having staff able to identify the signs of intoxication, and responding appropriately to the associated risks such as not being able to maintain one's own safety, physical risks and disinhibition.

https://findings.org.uk/PHP/dl.php?f=PHE_83.txt

In 2019 NICE published a set of quality statements⁵ aimed at improving the quality of care for people with co-existing conditions. The statements are as follows:

Statement one:

"People aged 14 and over with suspected or confirmed severe mental illness are asked about their use of alcohol and drugs."

Statement two:

"People aged 14 and over are not excluded from mental health services because of coexisting substance misuse or from substance misuse services because of coexisting severe mental illness."

Statement three:

"People aged 14 and over with coexisting severe mental illness and substance misuse have a care coordinator working in mental health services when they are identified as needing treatment from secondary care mental health services."

Statement four:

"People aged 14 and over with coexisting severe mental illness and substance misuse are followed up if they miss any appointment."

⁵ Co-existing severe mental illness and substance misuse Quality Standard [QS188], 2019: <https://www.nice.org.uk/guidance/qs188>

Support for you



What has helped the most? Joining Families Anonymous and working my own programme. Learning about addiction and mental illness. Counselling support. Supporting others.

Family member

Family members of those with co-occurring conditions consistently tell us that seeking support for themselves has been crucial. Often, family members are so concerned for their loved one's welfare and keen to get support for them, that they neglect their own needs and wellbeing.

Support Groups



It was really good hearing other people's experiences- you really learn a lot. You realise you're not the only one.

Family member

Most people supporting someone with co-occurring conditions focus on how they can help their loved one's recovery, but your own mental and physical health are important too.

If you haven't yet considered a support group, you might be surprised at how helpful it can be to talk to others who have had experiences of supporting someone through co-occurring conditions.

Organisations such as Al-Anon, SMART, and Mind hold regular support groups for families of people affected by substance use, mental health problems and co-occurring conditions.

You can also find a list of local support groups on Adfam's website.

How can support groups help?

Although support may differ from area to area, groups are usually led by a family support worker or someone who has lived experience of caring for someone with co-occurring conditions. Groups are informal and may be held weekly or less frequently. Since the Covid-19 lockdown, many groups meet online via Zoom or other video call platforms. Some groups may also have a closed Facebook page or a WhatsApp group. The common factor is that peer support groups offer the opportunity to talk about your experiences and share the experiences of others.

Peer support groups can offer some or all of the following:

- Information about mental health conditions
- Information about substance use treatment (including alcohol addiction)
- An opportunity to talk
- A non-judgemental shared space
- A social environment/activities
- Practical tips
- Advice on coping strategies
- Confidence building, relaxation and other wellbeing activities
- Training on boundary setting, family dynamics, first aid, mental health etc.

Your local carer's centre may also be able to offer:

- A carer's assessment and wellbeing payments
- Support groups
- Information and advice
- Social activities
- Wellbeing activities

Carer Support

You may not think of yourself as a carer, but if you're supporting someone with mental health needs and a substance use issue, your role is that of a carer. For some people this will be because they provide mainly practical help and for others it will involve giving emotional support or a combination of both. Either way, your caring role can be exhausting and time-consuming. It's important that you get the help and support that you need, to stay well and to be able to continue to support to your loved one. A good place to start is with a Carer's Assessment to find out whether you're entitled to any additional help.

The Carer's Assessment

Carers who regularly provide a substantial amount of care to a friend or relative, and their caring role impacts on their life, have the legal right to a 'Carer's Assessment'. These are carried out by social services, or sometimes by a Carer's Centre on their behalf.

What is a Carer's Assessment?

The purpose of the Carer's Assessment is to look at the help and support that you provide and the stresses that it places on you. It is your opportunity to tell social services about the things that could make caring easier and to discuss any concerns you may have about the future. Social services use the assessment to decide what help to provide. It should not assume that you want to continue to provide the same amount and level of support. It also does not matter if the person that you are caring for refuses services from Social Services.

You also have a right to an assessment if you intend to look after someone – for example, if the person you are caring for is in hospital and you expect to look after them when they return home. If you have already had an assessment but your caring situation has changed, you have the right to ask for a review. You also have the right to have a Carer's Assessment away from the person that you are supporting, if it is easier for you to talk openly and honestly about your situation.

How do carers get an assessment? Carer's Assessments are usually completed by a social worker. You can speak to your local Carer's Centre or GP, or contact Social Services yourself.

Some things you need to consider when preparing for the Carers Assessment:

- Do you get enough sleep?
- How is your health affected by your role?
- Do you get any time for yourself?
- Are your other family and friendship relationships affected?
- Do you have any financial concerns?
- Are you finding it difficult to juggle work and caring?
- Is the person you care for getting enough help for both their mental ill- health and their substance use?
- What sort of services might help you - services that give you a break, emotional support, help with household tasks, help with caring tasks during the day/night, activities for the person you care for, etc.
- Does the person you care for have difficulty moving about in the home?
- Would aids or adaptations to your home make life easier for you and the person you look after?
- Other interests – are you interested in training or adult education? Do you want to pursue leisure interests but feel you can't because of your caring role?
- How many hours a week do you care? Include all the time you spend with the person you care for and the tasks you do for them.
- How would you deal with emergencies and unplanned events - Do you know who to contact in an emergency?
- What support do you need right now? What might you need in future?
- Is this a review assessment? How has your situation changed and what new challenges are you facing?

You should be given a written copy of the Carers Assessment after it has been completed. This should summarise the discussions and form an action plan if social services are able to offer any further services as a result.

Carers and employment

If you're supporting a loved one, you may face difficult choices about balancing work, caring and finding support services to help stay in work. Today there are increasing numbers of people in the workplace with caring responsibilities.

Telling your employer

The usual advice is to tell your employer about your caring commitments. However, this is something that you need to consider carefully, because of potential prejudice and stigmatisation at work regarding co-occurring conditions.

If you do choose to speak to your employer, it can make dealing with an often unpredictable and complex situation easier. If you want to work, it is often in your employer's best interests to consider making reasonable changes to your work patterns so that you can continue supporting your loved one, too. Keeping the communication lines open between you and your manager is vital if you are to manage work and give your employer notice in time to make arrangements if you will be away. You could also speak to colleagues, a human resources manager or staff association to see if there is existing support available at your workplace.

Flexible working for parents and carers

Parents of children aged under 6 and parents of disabled children under 18, who have worked continuously as an employee for 26 weeks, have the right to apply to work flexibly for a need related to the care of the child. This right has existed for many years, but since April 2007, under the Work and Families Act 2006, the same rights have been extended to carers.

For this legislation a carer is defined as someone caring for an adult who:

- Is married to, or the partner or civil partner of, the employee
- Is a near relative of the employee (parent, parent-in-law, adult child, sibling, sibling-in-law, uncle, aunt, grandparent or step relative)
- Falls into neither category, but lives at the same address as the employee

How do carers apply?

You must apply in writing, explaining your caring responsibilities and the change you would like to make to your working arrangements. You should also consider the effect this might have on your employer's business and how this might be accommodated. The application must not be a repeat of one made in the previous 12 months and the employer must be given a reasonable time to consider and implement it. Employers have a duty to take requests seriously. Although they can say 'no' to a request, they will need to demonstrate clearly why this is so.

You can find more information in the ACAS leaflet 'The Right to apply for Flexible working', which can be downloaded from <http://www.acas.org.uk/index.aspx?articleid=803>

Flexible working arrangements. You could discuss the following options with your manager:

- Part/time, flexi/time, job-sharing or home working
- Annualised or term-time hours
- Flexible holidays to tie in with alternative care arrangements
- Compressed hours, staggered hours or shift work

For general advice on tax, allowances, money management and benefits advice, visit:

<https://moneyadvice.service.org.uk/en/articles/money-problems-and-poor-mental-wellbeing>

Supporting your own health and wellbeing

Whatever is going on with your loved one, it's essential that you carve out time and space for yourself. Self care is not a luxury, but is essential to staying well. Your wellbeing may feel very tied in with that of your loved one, but that doesn't have to be the case. You don't have control over your loved one's choices and behaviour, but you can control your own. Taking steps to reduce your stress levels and introduce relaxing and enjoyable activities back into your life is really important.

Below is a checklist of practical steps and ideas. Which will you do today?

Checklist of practical steps you can take to support yourself

Here are a few things that you can do to manage your own health and wellbeing. Again, this is a list of suggestions that you can try. They may not all be appropriate for you:

Request a carer's assessment at your local carers' centre	
Set and maintain boundaries with your loved one <i>Check out the information and videos for families on Adfam's website if this is difficult for you</i>	
Practice mindfulness or meditation (try a free mobile phone app)	
Talk to a trusted friend or family member about how you're feeling	
Keep a journal	
Make sure you have regular social contact	
Allow yourself some 'me time' and plan in activities that you enjoy	
Be realistic about the level and type of help you can offer your loved one	
Watch your own mental and physical health and take a break if you need to	
Join a carers' or peer support group	
Make sure that you eat regularly and well	
Visit your GP if you have symptoms of ill health or for a referral to a counsellor	
Establish clear house rules if the person lives with you	
Talk to your loved one about your needs and theirs	
Talk to other family members about their role in caring for your loved one	

Support if you're caring for children



She's great with him. We have him overnight if she's unwell. But yes, I suppose he does notice things. The other day he told me to "Go and take care of mummy."

Family member

Help for grandparents who care for their grandchildren

If you have responsibility for a grandchild(children) additional help may be available. You may be offering informal support, such as babysitting or taking the child(ren) to school, or your grandchild may live with you whilst their parent(s) is unwell, perhaps for long periods or permanently.

Like any parent, grandparents caring for their grandchildren are entitled in law to statutory help from their local authority if the child is assessed as being 'in need' as defined under Section 17 of the Children Act, 1989.

However, there are additional ways to potentially access help by changing the status of their relationship to the child.

There is often much conflict between parents with co-occurring conditions and grandparents over changing a child's legal status. This often inhibits grandparents from making changes, despite the increased help they may be entitled to. The following options need to be thought through very carefully and discussed with your family and with Social Services. They can be lengthy and stressful processes, and each one offers pros and cons in terms of financial support, legal status and parental responsibility or 'PR' (this is having legal recognition as the child's carer with all the associated rights and responsibilities).

Grandparents Plus and **Family Rights Group** can also offer support and advice, and we would recommend contacting them to discuss your personal circumstances before taking any decisions.

Grandparents Plus, a charity supporting kinship carers:
<https://www.grandparentsplus.org.uk/>

Family Rights Group, a charity advising grandparents and other relatives about their rights and options when social workers or courts make decisions about their children's welfare:
<https://www.frg.org.uk/>

When a child stays for 28 days or more with someone other than the birth parent, the carer has a legal responsibility to inform the local authority. They may be entitled to help from a social worker if the child is considered 'at risk'.

- **Special Guardianship Order.** This is awarded by a Family Court. Under this you are entitled to help such as a means-tested allowance. Under this order parental responsibility is shared by the special guardian and the birth parents.
- **Residence Order.** This directs that the grandchild lives with the nominated person/people (e.g. grandparents), so cannot be legally removed by the birth parents, although the parents retain Parental Responsibility. Any help is at the discretion of the local authority following an assessment, such as financial help through a resident's allowance.
- **Private Fostering.** As a grandparent, you can go through the process of becoming trained and recognised as a foster carer to your grandchild. However, this can be lengthy and there will be rigorous assessments, just as for other foster carers from outside the family. The local authority also retains parental responsibility for the child when he/she is in foster care. Foster carers are entitled to statutory help, such as an allowance, training, a social worker, access to a helpline, etc.
- **Adoption.** You could go through the legal process of **adopting** your grandchild. You would then have full Parental Responsibility. Adoptive parents are then entitled to the same help as any other 'parent', such as Child Benefit, tax credits, etc. Adoption can be costly and take a long time. There will also be rigorous assessments just as there are for

those seeking to adopt from outside the family. Some factors, such as age, may count against you if you are a grandparent, since the same criteria are often used as for any other prospective adoptive parent.

Parental Leave

This applies particularly to grandparents who care for the child(ren) of a someone with co-occurring conditions.

There is a statutory right to unpaid leave for carers of a child if they meet certain conditions. Carers must have legal parental responsibility for the child, be an employee with a contract of employment (agency workers are not eligible) and have worked for the same employer for a year. This entitles carers to:

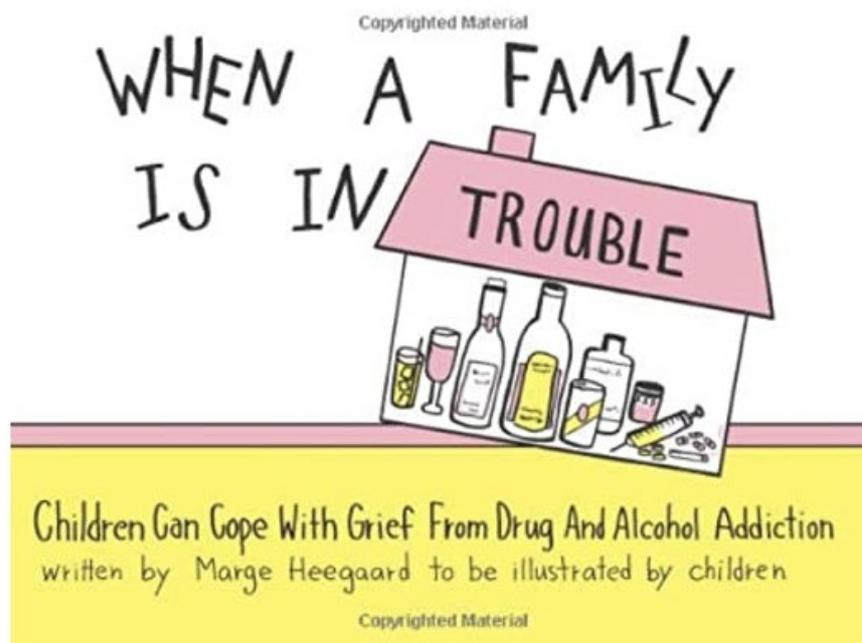
- 13 weeks off work for each child up to their 5th birthday.
- 18 weeks off for each disabled child up to the child's 18th birthday (a disabled child is defined as one receiving disability living allowance)

Where possible, employers and employees should negotiate parental leave at the workplace. If this can't be done then a fallback scheme operates. For this, leave should be taken in one-week blocks, with a maximum of 4 weeks leave for any one child in a year. Statutory parental leave is unpaid, but if carers are on a low income they may be entitled to Income Support. If you don't qualify for parental leave you could still ask your manager whether you can take annual leave, unpaid time off or consider flexible working options.

The following resources are useful for talking to younger children about problems that your family may be facing.

When a family is in trouble

This draw and write book is aimed at children aged 5+. It enables them to express their feelings about a parent's drug or alcohol use.



When someone has a very serious illness

Another draw and write book, this time with parental illness as the focus.



These resources are widely available from well known bookshops.

Wellbeing activities

The activities on the next three pages may help when you're feeling stuck or need a bit of a boost.

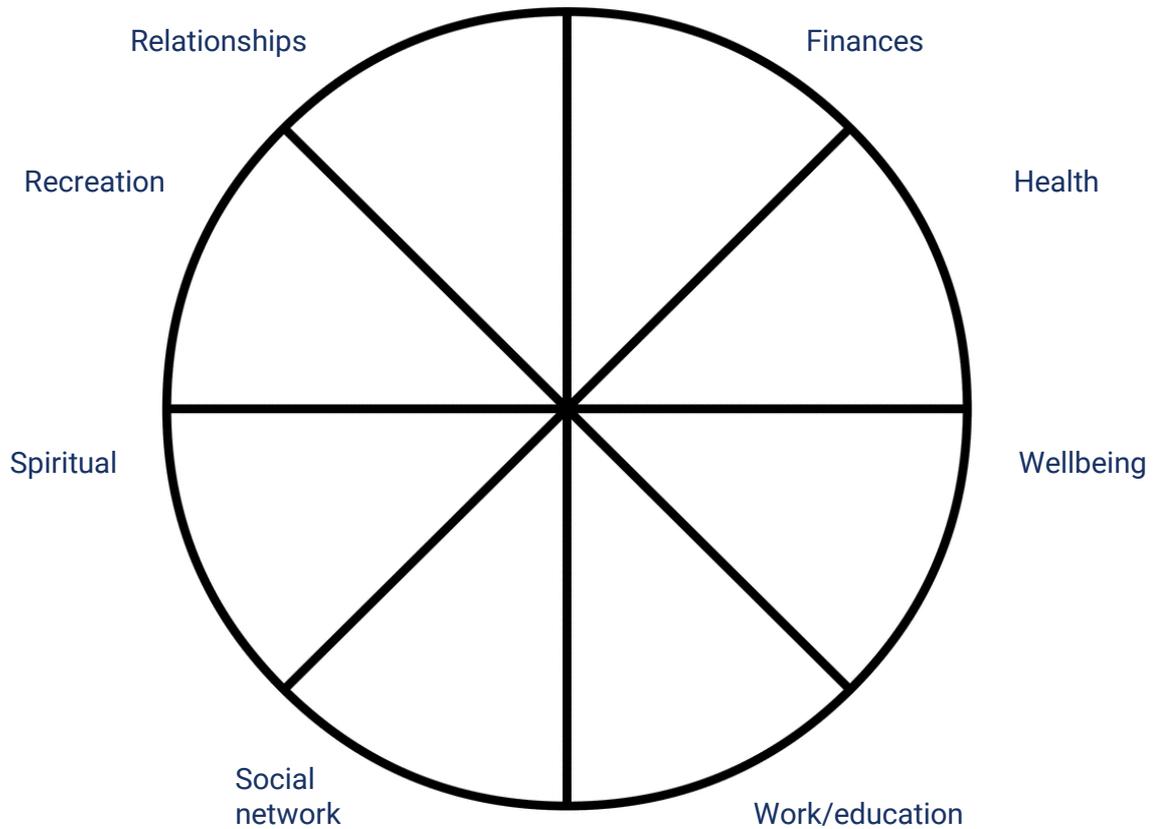
1. Five Ways to Wellbeing
2. Wheel of Life
3. My Self Care Chart

Five Ways to Wellbeing

A review of the most up-to-date evidence suggests that building these five actions into our day-to-day lives is important for well-being. Using the columns on the right (one for each day of the week), tick off an action once you've completed it. See how many you can tick off each day.

Connect	With the people around you. With family, friends, colleagues and neighbours. At home, work, school or in your local community. Think of these as the cornerstones of your life and invest time in developing them. Building these connections will support and enrich you every day.							
Be Active	Go for a walk or run. Step outside. Cycle. Play a game. Garden. Dance. Exercising makes you feel good. Most importantly, discover a physical activity you enjoy and that suits your level of mobility and fitness.							
Be Mindful	Be curious. Catch sight of the beautiful. Remark on the unusual. Notice the changing seasons. Savour the moment, whether you are walking to work, eating lunch or talking to friends. Be aware of the world around you and what you are feeling. Reflecting on your experiences will help you appreciate what matters to you.							
Keep Learning	Try something new. Rediscover an old interest. Sign up for that course. Take on a different responsibility at work. Fix a bike. Learn to play an instrument or how to cook your favourite food. Set a challenge you will enjoy achieving. Learning new things will make you more confident as well as being fun.							
Give	Do something nice for a friend, or a stranger. Thank someone. Smile. Volunteer your time. Join a community group. Look out, as well as in. Seeing yourself, and your happiness, linked to the wider community can be incredibly rewarding and creates connections with the people around you.							

Think about how happy you are with each of the areas of your life in the wheel below and give each triangle a score out of 10. Now decide which of these scores you'd like to raise and use the prompts below to decide what you're going to do to increase your score.



I would most like to work on...

1. _____

2. _____

Things I can do...

A

B

C

D

A

B

C

D

My Self-Care Chart

It's important to take care of your own wellbeing and have something to look forward to. Fill in the chart with enjoyable activities that you would like to do. Start with the small, today activities and work your way through to the larger things.

Things I can do:	Today	This week	This month	This year
For free				
That cost a little				
That cost a lot				
That I'll need to save for				

My self-care statement is:

Support for your loved one



Remember these are people struggling with really difficult challenges and should be regarded with respect for their struggles.

Family member

You may have just found out that your loved one has co-occurring conditions, or you may have been supporting them with multiple conditions for many years. Recovery for your loved one is not likely to be simple, speedy or smooth, but it can be possible. Remember that it is **not** your responsibility to 'fix' your loved one and some family members reach a point where they choose not to be involved at all. However, if you do choose to provide support, it's important to recognise the limits of this. You can only help them to help themselves. Whilst there are no quick fixes, there may be some practical ways that you can support your loved one's care, and these are detailed in this section.

Checklist of practical ways to help

The following suggestions may be of use if you are trying to provide practical care and support for your loved one. Tick the box on the right if this is something you could try. Consider that things you've done in the past are often worth trying again if your loved one is now feeling well. These may not all be appropriate or relevant to your loved one, and it may be a question of trial and error to find out what works best.

Ask them what help they want	
Keep a diary and call or text to remind them about appointments, medication etc.	
Hold a spare set of keys for their accommodation	
Suggest acupuncture or other complementary therapies	
Support them to carry out practical tasks e.g. shopping, cleaning	
Go for a coffee or other informal outing with them	
Focus on reducing harm rather than 'a cure'	
Encourage engagement with treatment and support services	
Discuss Powers of Attorney with them	
Educate yourself about their condition(s) and substance(s) use	
Discuss an appointeeship ⁶ with your loved one	
Encourage them to eat well and regularly	
Encourage them to take regular exercise	
Make an emergency or crisis plan	
Check they know what benefits they may be entitled to	
Discuss with them how they can maintain their independence	

⁶ Dealing with government benefits on their behalf. See: <https://www.gov.uk/become-appointee-for-someone-claiming-benefits>

Advocating for your loved one

If you feel that you or your loved one is not receiving the appropriate standard of treatment or support outlined in the national guidance, you may choose to advocate for better support or treatment for them. Unfortunately, having a co-occurring condition may mean that your loved one finds it harder to communicate or express their views and rights, or they may not be taken as seriously by professionals. Advocating for someone else means listening to their views and wishes and helping them to stand up for their rights.

As with any other support, it is important that you don't feel obliged to advocate for your loved one. However, some families like to do this. It can feel isolating supporting someone with co-occurring conditions, and some family members feel helpless. Engaging with services can reduce these feelings and, when effective, can improve things for everyone. This section provides some scenarios of when and how you could get involved in this way, if you would like to. Please bear in mind that every situation is different and your experiences will vary depending on how support services are structured in your local area. It therefore isn't possible for us to provide an exhaustive list of specific scenarios and advice.

If you would like more information or guidance, Adfam sometimes runs advocacy workshops for family members affected by a loved one's co-occurring conditions. These are funding dependent and run alongside specific political developments. To find out more, and for our latest event listings, please visit our website:

Scenarios where you might advocate for better support/ treatment for your loved one:

Your loved one is falling through the gaps between mental health and drug and alcohol services

Despite the national guidance, evidence⁷ and Adfam's own research experience suggests it is not uncommon for mental health services to exclude people because of co-occurring alcohol/drug use, or for drug and alcohol services to exclude people with severe mental illness.

If your loved one has presented at a local service and has been turned away because they are under the influence of drugs or alcohol, or their mental health/substance use needs are deemed too complex, the following statements from national guidance can be used to raise the issue with the service:

*"Upon first contact with a service ensure the person is referred to and followed up within secondary care, and that mental health services take a lead."*⁸

*"People aged 14 and over are not excluded from mental health services because of coexisting substance misuse or from substance misuse services because of coexisting severe mental illness."*⁹

⁷ <http://www.ias.org.uk/uploads/pdf/IAS%20reports/rp31042018.pdf>

⁸ Co-existing severe mental illness and substance misuse community health and social care services, 2016: <https://www.nice.org.uk/guidance/ng58/resources/coexisting-severe-mental-illness-and-substance-misuse-community-health-and-social-care-services-pdf-1837520014021> (Section 1.1.6, p7)

⁹ Co-existing severe mental illness and substance misuse Quality Standard [QS188], 2019: <https://www.nice.org.uk/guidance/qs188>

“Providers should have an open door policy for people with co-occurring conditions, supported by commissioners that enable services to respond collaboratively, effectively and flexibly to presenting needs, offering compassionate and non-judgemental care centred around the person’s needs, accessible from every access point”.¹⁰

Your loved one has not been given a care plan

The national guidance states that anyone with co-occurring conditions should receive an assessment and care plan. Mental health services should take the lead here. If this does not happen, the following statement can be used to raise the issue with the relevant service:

“Upon first contact with a service ensure that the focal patient is referred to and followed up within secondary care. Mental health services should take the lead in assessment and care planning”.¹¹

You have not been included in your loved one’s care plan

If your loved one would like you to be involved in their support/ treatment process, you should be offered information by their care co-ordinator and included in the care plan. If this does not happen, you can refer to the following national guidance:

“Involve the person (and their family or carers if the person wants them involved) in developing and reviewing the care plan (as needed) to ensure it is tailored to meet their needs. This includes offering the person information about the services available so they can decide which ones would best meet their jointly identified needs and goals.”¹²

Your loved one has been automatically discharged from their care plan because they missed an appointment

There may be scenarios where your loved one has missed an appointment with their mental health team or drug and alcohol treatment service. Services should recognise that people with co-occurring conditions have complex needs and a missed appointment should not lead to them being automatically discharged. If this happens the following national guidance may help:

¹⁰ Co-existing severe mental illness and substance misuse Quality Standard [QS188], 2019: <https://www.nice.org.uk/guidance/qs188>

¹¹ Co-existing severe mental illness and substance misuse community health and social care services, 2016: <https://www.nice.org.uk/guidance/ng58/resources/coexisting-severe-mental-illness-and-substance-misuse-community-health-and-social-care-services-pdf-1837520014021> (Section 1.1.6, p7)

¹² Co-existing severe mental illness and substance misuse community health and social care services, 2016: <https://www.nice.org.uk/guidance/ng58/resources/coexisting-severe-mental-illness-and-substance-misuse-community-health-and-social-care-services-pdf-1837520014021> (Section 1.2.4, p8)

“Ensure agencies and staff communicate with each other so the person is not automatically discharged from the care plan because they missed an appointment. All practitioners involved in the person's care should discuss a non-attendance.”¹³

Your loved one has been transitioned or discharged from support services and you do not know where to turn if their condition(s) deteriorates

“Before discharging the person from their care plan (the Care Programme Approach) or before they move between services, settings or agencies (for example, from inpatient care to the community, or from child and adolescent mental health services to adult mental health services) ensure:

-The discharge plan includes strategies for ongoing safety or risk management and details of how they can get back in contact with services.

-There are crisis and contingency plans in place if the person's mental or physical health deteriorates (including for risk of suicide or unintentional overdose).”¹⁴

How to go about advocating on behalf of your loved one

If you wish to advocate on behalf of your loved one, you can refer the service in question (e.g. mental health team, drug and alcohol team) to the statements above. Below you will find links to the full documents, and pages 6-8 of this toolkit also include sections of these documents:

- **Co-existing severe mental illness and substance misuse community health and social care services 2016**, Available online at: <https://www.nice.org.uk/guidance/ng58/resources/coexisting-severe-mental-illness-and-substance-misuse-community-health-and-social-care-services-pdf-1837520014021>
- **People with co-occurring conditions: commission and provide services, 2017** Available online at: <https://www.gov.uk/government/publications/people-with-co-occurring-conditions-commission-and-provide-services>

If you write a letter or email to the service manager, quote the relevant section and make sure you include a link to the document or the title of the document in the letter too. State briefly what your loved one's experience has been. Try to avoid blaming or angry statements. It works best to be assertive but constructive. Most individual workers are doing their best within the limits of resources available, or guidance they have been given. Raising an issue respectfully, calmly and factually is likely to get the best results.

¹³ Co-existing severe mental illness and substance misuse community health and social care services, 2016: <https://www.nice.org.uk/guidance/ng58/resources/coexisting-severe-mental-illness-and-substance-misuse-community-health-and-social-care-services-pdf-1837520014021> (Section 1.3.8, p12)

¹⁴ Co-existing severe mental illness and substance misuse community health and social care services, 2016: <https://www.nice.org.uk/guidance/ng58/resources/coexisting-severe-mental-illness-and-substance-misuse-community-health-and-social-care-services-pdf-1837520014021> (Section 1.1.11, p13)

If raising the issue with the relevant service manager does not lead to improved care for your loved one, then you may wish to contact your local NHS Trust (if it is an NHS service) or the local Health and Wellbeing Board. Each local authority has a Health and Wellbeing board which oversees the services provided. You can find this by searching online the name of your local authority and 'health and wellbeing board'. For more information about Health and Wellbeing Boards, please see this guide produced by Compact Voice:

http://www.compactvoice.org.uk/sites/default/files/engaging_with_health_and_wellbeing_boards.pdf

If your loved one is in hospital and you feel their needs are not being properly addressed or staff are not responding to your or their attempts to discuss better care, then PALS (Patient Advice and Liaison Service) can support you or your loved one to raise issues about their care. For more information, visit the NHS website:

<https://www.nhs.uk/common-health-questions/nhs-services-and-treatments/what-is-pals-patient-advice-and-liaison-service/>

Political advocacy

Finally, if you feel that you or your loved one is not receiving adequate support, you can contact your local MP, calling on them to ensure that local services are adhering to the national guidance and that there is adequate support and funding available for services helping those affected by co-occurring conditions.

Part of Adfam's work includes advocating for political change. We do this by running campaigns and lobbying the government to increase support for families affected by their loved one's drug and/or alcohol use. If you are interested in learning more about our advocacy and campaigning work, or would like a template to write to your local MP about these issues, please visit:

MIND mental health advocates

If you feel that you or your loved one are not receiving the appropriate standard of treatment/ support you can also apply for a volunteer to advocate on their behalf. The mental health charity MIND provides information about how to find a volunteer who can advocate for you and your loved one.

Please visit: <https://www.mind.org.uk/information-support/guides-to-support-and-services/advocacy/finding-an-advocate/>

Adfam Resources

The following resources are available on Adfam's website: <https://adfam.org.uk/>

Challenging Stigma

Tackling the prejudice experienced by the families of drug and alcohol users

A Partnership Approach

Supporting families with multiple needs

Making it happen

Support for families and carers affected by someone else's drug or alcohol use

Consultation findings for the BEAD Project (Bereaved through alcohol and drugs)

Between a rock and a hard place

How parents deal with children who use substances and perpetrate abuse

No-one judges you here

Voices of older people affected by a loved one's substance use

Living with a drug user: for partners of drug users

Booklet answering questions that partners may have

Living with a drug user: for the parents of drug users

Booklet answering questions that parents may have

Setting up a family support group

A guide to help people to set up support groups for affected others

"We count too" – Good Practice Guide and Quality Standards for work with family members affected by someone else's drug use.

Other resources

The mental health charity, Mind, has produced a leaflet called **Understanding the mental health effects of recreational drugs and alcohol** <https://www.mind.org.uk/media-a/2951/recreational-drugs-and-alcohol-2016.pdf>

Better care for people with co-occurring mental health and alcohol/drug use conditions. A guide for commissioners and service providers. Available online at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/625809/Co-occurring_mental_health_and_alcohol_drug_use_conditions.pdf

Useful contact list

This is a selection of organisations you may find helpful. This list is by no means exhaustive and only covers national organisations, so doesn't cover those that are local to your area. Please visit <https://adfam.org.uk/help-for-families/useful-organisations> for a list of useful organisations that is updated regularly.

Most of the telephone numbers provided are available during normal office hours. However, some of the larger charities are available during some night hours as well as during the day. Adfam cannot guarantee the service of these organisations, but it does give an idea of what help is available.

<i>Al-Anon Family Groups</i> 020 7403 0888 www.al-anonuk.org.uk	Support for anyone who is, or has been, affected by someone else's drinking.
<i>British Association for Counselling and Psychotherapy</i> https://www.bacp.co.uk/	An online search facility for professional counsellors across the country
<i>Carers UK</i> 020 7378 4999	Information, advice and support for carers
<i>Drinkline</i> 0300 123 1110	Advice for those worried about their own, or a loved one's, alcohol use.
<i>Families Anonymous</i> 0845 1200 660 www.famanon.org.uk	Support for families and friends concerned about drug abuse or related behavioural problems.
<i>FRANK</i> 0300 123 6600 www.talktofrank.com	National drug information service with fact-files and FAQs.
<i>Mind Helpline</i> 0300 123 3393	Helpline providing advice and support for anyone experiencing a mental health problem.
<i>National Domestic Violence Helpline</i> 0808 2000 247	Provides a free, fast emergency injunction service to survivors of domestic violence regardless of their financial circumstances, race, gender or sexual orientation.
<i>Release</i> 020 7324 2989 www.release.org.uk	Organisation providing services to meet the health, welfare and legal needs of drug users and their families
<i>Rethink Mental Illness</i> www.rethink.org	Support groups, local services and information
<i>Revolving Door Agency</i> www.revolving-doors.org.uk	National charity supporting people affected by mental ill health and the criminal justice system
<i>Samaritans</i> www.samaritans.org 116 123	Immediate emotional support for anyone in emotional distress, struggling to cope or at risk of suicide.
<i>SANE</i> www.sane.org.uk	Charity supporting individuals and families affected by mental illness
<i>Shelter</i> www.shelter.org.uk	Support for people who are homeless or in housing need
<i>Turning Point</i> www.turning-point.co.uk	Works with individuals and their communities in the areas of drug and alcohol misuse, mental health and learning disabilities. Has particular expertise in working with people who have complex needs and are facing multiple social challenges.

Local

Please note any useful information about support in your local area below.

About Adfam

Adfam is the only national charity tackling the effects of alcohol, drug use or gambling on family members and friends. We improve life for thousands of people. Our mission is to do this by:

- empowering families and friends to get the support they need.
- building the confidence, capacity and capability of frontline practitioners to provide effective services.
- influencing decision-makers to understand the needs of thousands of people coping with a family member or friend's drink, drug or gambling problem

Adfam has produced a number of resources for families and professionals, that can be found in the resources section at the back of this toolkit. You can also find out more about our work with families, professionals and policy makers on our website:

<https://adfam.org.uk/>

About our work supporting families affected co-occurring mental ill-health and substance use conditions.

In 2018, Adfam received funding for a project to explore the experiences of families supporting a loved one with co-occurring mental ill-health and a substance use condition. The aims of the project, funded by the Sir Halley Stewart Trust, were to:

- Raise awareness of these issues among professionals, such as social workers, nurses, mental health practitioners, substance use workers and other social care providers
- Increase understanding of the impact of a co-occurring condition on family members
- Identify positive practice in working with and supporting family members

To help us to understand the impact that this can have, we spoke to families across the country through 6 focus groups and 20 telephone interviews (also including professionals) and heard a vast range of experiences. We learnt that many families supporting a loved one face barriers to support - such as stigma, strain on services, lack of understanding among professionals and a negative impact on their own mental and physical health. From this information, we have produced this toolkit for families.

For more information about our work supporting families with co-occurring conditions, please visit: <https://adfam.org.uk/about-us/projects/dual-diagnosis>