

# Together with friends, family and neighbours

Spring 2023 | Carer insights and updates



Welcome to our second issue of Together with friends, family and neighbours.

With carers and staff, we've made this newsletter to share information from our Trust and local communities. It also includes support and resources.

We work alongside people who care for their partners, neighbours or friends.

We know that many unpaid carers may not identify as one, or know they are one.

In this newsletter, when we say carers, we mean anyone who provides unpaid support that someone in our care relies on.



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# Coming soon... Your chance to chat with fellow carers for Carers Week 2023

*We are pleased to share this invitation with you, from our carers working group.*

Dear fellow carers,

As we approach Carers Week, we wanted to reach out to you to invite you to events for carers we are hosting around our Trust's area. As people with experience of being carers, we understand how challenging and overwhelming it can be to care for someone with a mental illness or learning disability, which is why we believe it's essential to connect with others who are going through the same experiences.

Our event is an informal gathering for carers like you, hosted by fellow carers. We want you to feel supported, heard and valued as we discuss and share our experiences, challenges and triumphs. It's a great opportunity to connect with others who understand what you're going through and to feel a sense of belonging within a community.

We will also provide you with information about involvement opportunities within Tees, Esk and Wear Valleys NHS Foundation Trust, so you can have a say in how services are developed and delivered. We value your opinion, and we believe that you have

a vital role in shaping our services to meet the needs of our patients and their families.

We have four events scheduled in different

locations, and we encourage you to attend the one that's most convenient for you. You're welcome to bring a friend or family member with you.

You can find the details for each event on the next page.

We hope you can make it to one of these

events, and we look forward to welcoming you with open arms. Let's come together as a community to support each other and create a brighter future for our loved ones and ourselves.

You can keep an eye on the Tees, Esk and Wear Valleys NHS Foundation Trust website for more detail as we approach Carers Week 2023.

Best regards,

**The Carers Working Group**



## Spotlight on...

It's a great opportunity to connect with others who understand what you're going through and to feel a sense of belonging within a community.

### Carers Working Group



**Date:** Thursday 8 June 2023

**Time:** 10am

**Location:** West Park Hospital



**Date:** Thursday 8 June 2023

**Time:** 2-7pm

**Location:** Main Reception, Lanchester Road Hospital



**Date:** Friday 9 June 2023

**Time:** 10am

**Location:** Dalesway, Roseberry Park Hospital



**Date:** Wednesday 7 June 2023

**Time:** 10am

**Location:** St Sampson's Square, York

### Research trial for autistic people experiencing low mood

We are looking for volunteers to take part in an autism depression trial – exploring whether the talking therapy ‘guided self-help’ is an effective treatment for low mood and depression, in autistic individuals.

To take part in the study participants will need to:

- be aged 18 years or over.
- be experiencing symptoms of low mood/depression.
- have a clinical diagnosis of autism.

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**If you're interested in talking part:**

Visit [www.bristol.ac.uk/adept](http://www.bristol.ac.uk/adept)

Or email [TEWV.researchanddevelopment@nhs.net](mailto:TEWV.researchanddevelopment@nhs.net)

#adept2study



### Reminder: check what benefits you can get

We understand that knowing what financial help you may be able to claim as a carer can be confusing. A simple solution can be using an online benefits calculator. You'll need to enter information about your circumstances and situation. From this, you'll be given a good idea of the benefits you could be entitled to.

You can check if you're entitled to Carer's Allowance and other benefits with the entitled to benefits calculator.

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**Use the entitled to benefits calculator:**

[www.entitledto.co.uk](http://www.entitledto.co.uk)



## Spotlight on...

### Introducing our amazing Carers Working Group

Our Trust's Carers Working Group meets monthly. The group aims:

- to recognise the voice and specific needs of Carers.
- to listen and work together with Carers to improve their experience at every level of the Trust.
- to enable Carers to have their specific needs recognised and met.
- to establish the role of the Carer within the Trust's Care Group Boards and subsequent Trust networks.

We are proud of the amazing successes that have come from the group so far.

For example, the group have organised powerful events such as conferences and open events, as well as co-creating a website hub (pictured below) for

Tees, Esk and Wear Valleys NHS Foundation Trust carers.

The group have been instrumental in giving valuable feedback from a carer perspective. We are really grateful for the compassion, time and commitment given by members of the group.

Many of our members are driven to make improvements and support others. Meetings are on Microsoft Teams. They currently take place from 9-10.30am on the fourth Friday of every month.

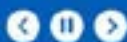
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**If you are interested, new members are always welcome to come along. To get involved you'll need to be an involvement and engagement member. To find out more about this, please email [TEWV.involvementandengagement@nhs.net](mailto:TEWV.involvementandengagement@nhs.net)**

#### Friends, families and neighbours

If you provide unpaid support to someone in our care, we value you and your knowledge. Support, information and practical advice is available.

Carers' hub →



The group aims to recognise the voice and specific needs of Carers.

From the group's terms of reference

# Anthea's recommended videos: kind and helpful insights about being a carer

We understand that being a carer for someone with a mental health illness or learning disability can be challenging and at times, overwhelming. That is why we want to share some resources that may be of help to you.

Anthea, from the patient and carer experience team, recommends three videos that may offer some insight and comfort.

The first is "[What we want you to know about being a young carer](#)," a film from the West Yorkshire Health and Care Partnership. This short video shares the experiences of young carers and offers advice for those who may be in a similar situation. It is a valuable resource for both young carers and those who support them.

The second and third videos are both poems written by a carer, Matthew McKenzie. The first poem, "[The hidden link](#)" is a powerful and emotional piece that speaks about the essential role of being a carer.

The second, "[The Carers Network](#)," offers a more hopeful message about the power of having connections with fellow carers. Both poems provide a unique perspective on the carer experience and are worth watching.



We hope that these videos provide some comfort and support to those who care for someone. It is important to remember that you are not alone, and there are resources available to help you.

**"We hope that these videos provide some comfort and support to those who care for someone. It is important to remember that you are not alone, and there are resources available to help you."**

If you are struggling or need further support, please do not hesitate to reach out to your local carer support group. They can offer guidance and connect you with additional resources that may be of help. There is information about local support groups on the

Carers' Hub of the Tees, Esk and Wear Valleys NHS Foundation Trust website.

Thank you for all that you do as a carer. Your dedication and care are truly appreciated.

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**You can watch the videos on YouTube. Simply search using the title of the video.**

**Or, if you are reading this online, you can click the hyperlinks in the text.**



# Film created to give reassurance to carers of patients in our secure services

A film has been created to give detail about our staff and facilities at Ridgeway, Roseberry Park Hospital, Middlesbrough. Ridgeway offers secure inpatient services. Having someone you care for admitted to a secure service can be daunting. The film was created after a meeting where Ridgeway carers asked if it was possible to have something more detailed that could help them understand what Ridgeway is, but also what it is not.

The new film tackles misconceptions and aims to put carers at ease, by focusing on the support and recovery journey of their loved one. Filmed over three days, the video includes a wide range of staff explaining how their role supports patients. The film also includes footage of several areas of the hospital, showcasing the high-standard facilities, including our community café, sports hall and gym.

Carers were invited to watch the film before it was shared for public viewing. We wanted to ensure carers found the film informative and useful if they were the carer of a new admission patient. We were thrilled to receive a positive response, with the film being described as 'fantastic from start to finish'.

The film is now available for all carers, both existing and new. We understand that having a loved one admitted to a secure service can be a difficult time. We hope that this film helps to answer any questions you may have and puts your mind at ease. We are here to support you and your loved one every step of the way.

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You can watch the film on our Trust website on the [Ridgeway page](#).



## Tom's story

# Carers play key role in helping loved ones with eating disorders



People who develop an eating disorder face an uphill struggle for recovery – and so do their loved ones.

Tom Capeling (above) fought battle after battle to save his daughter from the condition that was ruining her life and, only now she is in recovery, can he finally relax.

“You might not think of yourself as a carer, but whether you are a parent or a loved one, living with someone with an eating disorder can be awful,” said Tom, 59, from Sunderland.

“It wants that person to be alone and isolated and makes them do anything to turn others away. It’s like living with two people – the person you love and someone else hidden inside.

“You catch glimpses of the person you know, but the rest of the behaviours are the disorder. You have to remember the person you love is still in there and try to get through to them.”

Tom’s daughter first developed an eating disorder at 12. For two to three months she refused to eat and even rationed her drinks. The family found it heart-breaking to deal with.

“Luckily, it didn’t last long. It was awful at the time, because she was totally out of control, but she managed to fight off the feelings by herself,” said Tom.

“But, when it happened again at 18, she just didn’t have the strength to fight back. Her feelings were just too powerful. Within three months she was admitted to hospital.”

The teenager’s second eating disorder took her whole family by surprise. Indeed, it started as stomach cramps and pain – which she tried to control by reducing her food intake.

“This time around she wasn’t hiding anything from us. She told us about the pain and explained that if she ate less, then she experienced less pain,” said Tom.

Tests at the Freeman Hospital, however, ruled out any stomach problems. Instead, it was determined it was actually an eating disorder. Within months she was in a TEWV hospital.

“She had been open and honest this time, not hiding anything – at least first,” said Tom. “This was a very uncommon way for an eating disorder to present – very atypical indeed.

“Because she was atypical, it’s difficult to say what started it off. It was just a mystery pain.

Then, over time, it presented in a normal way. There was no specific trigger point at all.

“As the months went on, things got worse. The eating disorder was always ahead of us. It was

**“Parents might not see themselves as carers, but they are. If they want to help a loved one, they need to get to know the illness better; to understand how to try and really help.”**

**Tom Capeling**

## Tom's story

like an inner voice in my daughter's head, always controlling everything she did.

"The voice is very manipulative, very clever. If someone eats, the voice punishes them – or congratulates them on missing a meal. There was no way to win against the voice."

Tom's daughter was eventually admitted to Birch Ward, at TEWV's West Park Hospital in Darlington, after her condition deteriorated. It would not be her only time as an inpatient.

"People with an eating disorder want to push everything away. They lie, they hide, they make things difficult for those who love them. But it's not them, it's the illness," said Tom.

"When my daughter first went in to hospital, we thought that was it – she would be made healthy. But that's not what happened – it's not a quick fix. It can be a long, long haul.

"Parents might not see themselves as carers, but they are. If they want to help a loved one, they need to get to know the illness better; to understand how to try and really help.

"The earlier an eating disorder is caught, the more chance there is of a faster recovery and not ending up in hospital. As a carer you need to find out as much information as possible."

Tom's daughter was hospitalised five times in four years due to her condition, spending a total of a year as an in-patient at West Park, a Glasgow unit and the RVI in Newcastle.

At first she fought the sections – as the voice in her head didn't want to be confined – but during the fifth hospital stay something changed. She finally accepted the offer of help.

"She said it was like a switch had been turned on to give her the strength and power to fight the illness," said Tom.

"It was unreal. To see her want to fight this, to want to get better, it was something we had all hoped for.

"At first we couldn't believe it, but then she kept it going and went beyond any targets. That's when we realised she really meant it. We could see her improving all the time.

"It was a daily fight for her for almost a year after she was finally released from hospital, but now she says she doesn't have the voice at all. It is amazing and we are so grateful."

Tom's experiences have led him to join The Lived Experienced Advisory Group – run by TEWV and our partners Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust – to help steer the course of future support for both patients and carers.

Group members provide feedback to staff on what it is really like to live with people with an eating disorder – as well as raising awareness of the need for individual care and help.

"We have to be honest about this – carers need help too. Looking after someone with an eating disorder is a battle, and we need real support during this hard fight," said Tom.

"But it is possible to get through. I have hope for the future now – and my daughter has hope too. It's taken a while, but she is getting her life back together and has her own flat now.

"Some people might say that an eating disorder is always with you, but my daughter doesn't. She feels fully recovered – which shows you can recover and go back to a normal life."



## Carers join forces with patients and staff at co-creation workshop in Northallerton

On 30 January 2023, over 50 people attended a hybrid co-creation workshop held at North Moor House in Northallerton.

The event aimed to foster relationships and explore how to embed co-creation.

The attendees included representatives from Children and Adolescent Mental Health Services, Mental Health Services for Older People, Learning Disability Services and Adult Mental Health Services, as well as support services such as IT, People and Culture (HR), Organisational Development, and Information Services. Governors

and involvement members, including carers, were also present. The workshop planning and delivery

were co-created with a working group made up of 50% staff and 50% involvement members.

Speaking about the event, Charles Nosiri, one of our Lived Experience Directors, said: "Bob Etherton and Joanne Clare, members

of the event planning group, did an excellent job of introducing the day and gave powerful presentations. Bob even brought his paintings along to share with the attendees."

**"Bob Etherton and Joanne Clare, members of the event planning group, did an excellent job of introducing the day and gave powerful presentations."**

**Charles Nosiri, Lived experience director**

## Co-creation in action

The two main objectives of the workshop were to facilitate a shared understanding of co-creation and establish a TEWV Co-creation Board. Participants shared their views on what organisational mechanisms, structures, and governance need to be in place to support co-creation and shared-decision-making fully.

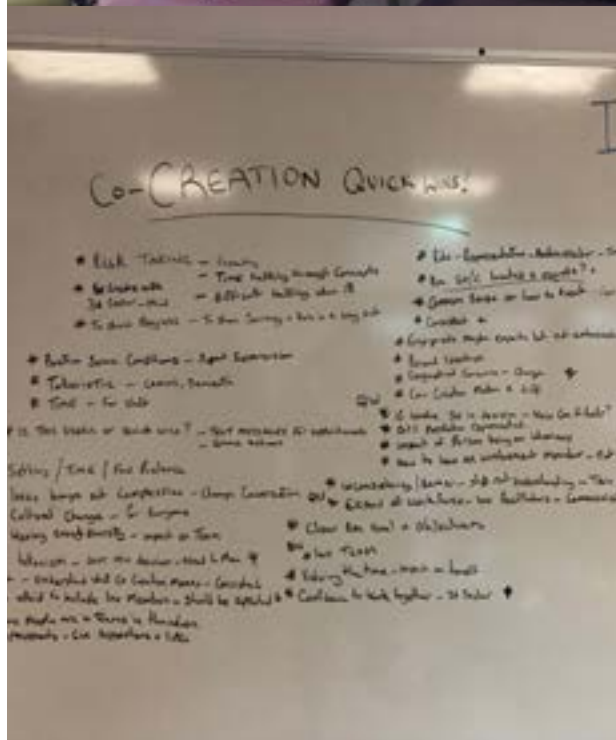
The workshop was well-received, and attendees found it engaging. The attendees contributed significantly to establishing the Co-Creation Board, and there is already momentum to hold a follow-up workshop as soon as possible.

The event was a great success, and we would like to thank all of our carers and patients who attended and contributed their valuable involvement.

## What's next for co-creation?

Lived Experience Director, Charles Nosiri, explains some of the plans that have been set into motion by the event:

1. Feedback from the workshop has been grouped into themes by the Event Planning Team. These will be used to inform other workshops.
2. Plans for a follow-up workshop with participants to include our external and community partners.
3. Plans for bespoke events for CAMHS and LD services.
4. Plans to develop and finalise a North Yorkshire, York and Selby Co-Creation Workplan from these events.
5. We will look to share the NYYS Co-Creation Workplan with the North Yorkshire, York and Selby Care Group Board, so they can be implemented as soon as possible, where practical.
6. The Durham, Tees Valley and Forensics care group also held a co-creation event on 6 February 2023. Insights from that will also be taken into consideration.



Above: Pictures from the event including artwork from Bob Etherton

# Making strides in improving quality of life for those with learning disabilities in Durham



*This article has been written by Claire Donnelly, Primary Care Liaison Clinical Lead Nurse, and Faye Rowley, Primary Care Liaison nurse.*

*The pair have been working to improve the lives of patients with learning disabilities in Durham through a national project called STOMP.*



*STOMP stands for stopping over medication of people with a learning disability, autism or both with psychotropic medicines.*

*In this article, Claire and Faye provide an explanation for carers of people with a learning disability, autism, or both, about what STOMP is and how it may be able to improve your loved-ones quality of life.*

We've been working collaboratively with Primary Care, Secondary Care, Parents, Carers and providers to embed STOMP. It's all about improving peoples' quality of life and giving patients and carers an understanding of the medication and the side effects.

The STOMP guidelines were first produced in 2016. Our aim is to improve a patient's quality of life by reducing the potential harm of inappropriate psychotropic drugs.

Because we are carefully considering the quality-of-life of each patient, we focus on health promotion such as:

- monitoring the side effects of the psychotropic medicines
- reviewing the indication of why the person is prescribed the psychotropic drug
- reviewing how long they have been prescribed this drug.

We ask questions that consider the wider wellbeing picture. For example, does the person have the right support? Could activities or interventions be offered rather than medication?

### **Q. What does STOMP stand for?**

Stop the over medication of people with Learning Disabilities

### **Q: What is a psychotropic drug?**

A psychotropic medication is a medication that effects the brain. People with a learning disability are 10x more likely to be prescribed this medication than an individual who does not have a learning disability.

### **Q: Who do we support under STOMP?**

STOMP is for people who:

- are 18 or over
- have a diagnosed Learning disability
- are not under secondary Psychiatry
- are prescribed psychotropic medication for your behaviour or there is no indication or diagnosis.

**Q. Will every patient be taken off their medication?**

No, STOMP is not for everyone. We recognise that medication works for some individuals and alternatives have been tried and tested.

**Q. What does the STOMP review entail?**

It is a medication review and is a part of the annual health check.

We visit patients at home, GP surgeries or a place they are familiar with and comfortable with. We ask questions about their medication and go through an assessment called a LUNSER. This tells us if the individual is experiencing any side effects from prescribed medication.

We will complete a quality-of-life assessment to identify any additional support needed or if changes need to be made to improve a patient's quality of life.

If the patient requires a physical health check, we can carry these out too.

**Q. What if the person I care for has limited communication?**

We use some alternative communication tools to ensure that the individual has a voice and has their say about their medication. We can also gather information from the closest people to them and take their views or any concerns on board.

**Q. What happens if my medication is reduced?**

We support patients through their STOMP journey. This includes regular visits for support both the individual and the family, carers, or care provider. We monitor physical health, presented behaviours and ensure there are no adverse effects to the reduction plan.

**Q. Who will be involved in medication reduction plans?**

This will be down to the professional who prescribed the medication. We also have a panel of professionals who have specialist skills and knowledge around Psychotropic medication. We can liaise with the panel to ensure the reduction is safe.

**Q. What if the person who I care for becomes unwell or worse after a medication reduction?**

This will be picked up early. We will be in contact with the patient regularly and they would have the STOMP teams contact details if they have any concerns or issues. We monitor the individual as often as it is needed, and we would ensure the intervention is put into place in a timely manner. This may require a specialist service supporting the individual for a short time or the prescriber increasing the medication slightly to a more therapeutic dose.

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**You can get in touch by email or phone:**

**[tewv.stompprimarycareliaisonnurses@nhs.net](mailto:tewv.stompprimarycareliaisonnurses@nhs.net)**

**Claire Donnelly – 07789031212**

**Faye Rowley - 07825899008**

## Our partners and local organisations

### How Stamp it Out are tackling mental health stigma

*We caught up with Karen from Stamp It Out in Durham about the important work in our area around mental health stigma. Here's what she wanted to share.*

Hello, my name is Karen and I am the Partnership Manager and an Anti-Stigma Ambassador for the Stamp It Out Partnership Hub.

Here is a little bit about us. We are led by Anti-Stigma Ambassadors who have mental health lived experience. We work in partnership with groups and organisations using our 3 focus areas of Children & Young People, Workplaces and Communities.

We address and challenge barriers around mental health stigma and discrimination in partnership by promoting and educating to raise awareness across County Durham through our training packages, roadshows and by attending events.

We use 'Social Contact' conversations where someone with lived experience has a conversation with someone who may or may not have lived experience in order to change perceptions and attitudes; along with the use of our toolkit of resources.

We have a range of opportunities for involvement, if anyone would like to know more about subscribing to be a member, becoming an Anti-Stigma Ambassador or just would like to know more!

**Please get in touch with us via our website**

**[www.stampitoutcountydurham.co.uk](http://www.stampitoutcountydurham.co.uk) or**

**email [stampitoutdurham@gmail.com](mailto:stampitoutdurham@gmail.com)**

### Durham County Carers Support



Durham County Carers Support are the primary Carer Support Service in County Durham and Darlington - we provide free high-quality services and support to unpaid Carers over the age of 18.

Durham County Carers Support offer a one-stop shop for information and support available.

Durham County Carers Support can provide:

- One to one tailored support
- A listening ear
- Help with completing forms and benefit applications
- Access to grants and funding
- Help to take a break from your caring role
- Signposting to relevant organisations who can also support
- Groups and events
- Training on various topics
- Counselling sessions
- Carers Discount Card
- Carers Emergency Card
- Online support for Carers and help getting Carers online
- Free debt support
- Money advice
- Specialist Parent Carer Support including Parent Carer Needs Assessments

Durham County Carers Support's mission is to improve the lives of unpaid Carers.

The organisation supports over 24,000 Carers across County Durham and Darlington.



## Our partners and local organisations

### A day in the life of a Carer Support Co-ordinator at Durham County Carers Support

#### 9:30am – 2:30pm Triage

I spoke to a Parent Carer who had registered with us to access a Parent Carer Needs Assessment. I discovered that her partner and parents are a massive support in caring for her daughter too. I suggested they register with us as they are all in a Caring role. She was surprised as she thought that only the main Carer could sign up for support. I referred her to our Specialist Parent Carer Team and not long after I noticed her partner and her parents were on our Triage register. They didn't all need the same kind of support. Her parents wanted the Carer Discount Card so they could take their granddaughter out for the day with free access to different places. Her partner wanted to sign up to our free counselling service as he was struggling in his caring role. During Triage we discuss how the Carer is managing and what we can do to support them as everyone's needs are different.

#### 1pm-2:30pm Carer Support Group

At this week's Carer Support Group we had a special guest from the social prescriber network and the Carers found this really helpful. We also had time for a cuppa and a chat. The Carers had an opportunity to talk to each other about their own challenges and some funny stories came out around their caring role which left the group on a high.

#### 3:30-4pm Supporting a Carer with a PIP application

Before we started the application, I had sent the Carer a guide to applying for Personal Independence Payment that our Benefits expert produced. This explains how points are awarded so we knew in advance that there was a high chance the cared for would be awarded PIP at some level. As always when completing a PIP form, we established that there were many things that the Carer did for her partner. Carers don't always realise themselves how much they do for their partner/family member/friend as they do it so often they regard it as routine, but the cared for could not manage without them.

#### 4:30-5pm Carer struggling with Debt

This Carer was struggling to pay his bills as a result of debt he wasn't able to manage. I explained that we know lots of people struggle in silence when it comes to debt but assured him that he would be supported in a non-judgemental manner and all information would be kept strictly confidential. I referred the Carer to our Debt support team.



#### For more information about Durham County Carers Support

Call: 0300 005 1213

Text: 07860 017632

Email: [admin@dccarers.org](mailto:admin@dccarers.org)

Web: [www.dccarers.org](http://www.dccarers.org)

You can now sign up for support directly from the website: <https://dccarers.org/sign-up-for-support/>

We have a lot to be proud of, yet we don't always provide a good enough experience.

**In 2020  
you told us...**

**1 Our purpose...**

For people to lead their best possible lives.

**3 We want to be...**

We will co-create safe and personalised care that improves the lives of people by involving them as equal partners. We will listen and always be respectful, compassionate and responsible.

**4 We can achieve this by always living our values:**



Respect



Compassion



Responsibility

**5 Our three big goals**

**Goal 1**

To co-create a great experience for our patients, carers and families:

- Outstanding compassionate care, all of the time.
- Access to the right care for you.
- Support to achieve your goals.
- Choice and control.

**Goal 2**

To co-create a great experience for our colleagues:

- Pride because your work is meaningful.
- Involved in decisions that affect you.
- Well led and managed.
- Workplaces that are fit for purpose.

**Goal 3**

To be a great partner:

- Share an understanding of our communities
- Work innovatively across organisational boundaries.
- Be recognised for what we have achieved together.

Your opinions are important. Get involved