

Champions for change

Working together with families,
carers and friends as partners
in mental health recovery

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Brisbane South PHN is the lead agency for the Partners in Recovery program supported by the Australian Government





The overarching theme of this booklet is that recovery becomes more probable when families and carers are involved as equal partners.

The experiences of families and carers can involve numerous challenges which unfold over many years and even a lifetime. Families and carers are often the first to know when treatment is needed. Families and carers play a critical role in how people living with a mental health difficulty are included in community and family life.

Even more important is that enduring family, friendship and carer relationships exist where there is a feeling of belonging.

This booklet is in part about ways of preserving those relationships over a lifetime and preventing unendurable stresses and strains which can be avoided through a respectful partnership involving the person, their families, carers and friends, and care providers from the mental health system.

Foreword

This booklet grew out of a *Family and Carer Forum* held in March 2015 in Brisbane South, attended by over 70 family members and carers.

The forum was an opportunity for families and carers to share ideas and advice about the value of their role in the recovery of their family member or friend. The booklet is intended to share discussion points and practical ideas for how mental health service providers can work in partnership with people who play such a central role in the wellbeing of people living with a mental health difficulty.

The *Family and Carer Forum* emerged from an earlier study that documented a Family Engagement and Support Framework.

This includes important advice across four key domains including access to services, being partners in supporting recovery, information and education, and family health and wellbeing.

Across all of these domains there are important ways of working which strengthen families and carers and which help to avoid unnecessary burdens and avoidable gaps in how treatment and recovery unfold.

This booklet is based as much as possible on the key messages that families and carers want care providers to know:

That recovery is more likely if they are involved as a partner and that life for a person with a mental health difficulty is better if relationships and ties with families, friends and carers are as strong and healthy as possible.

In the most simple terms, families and carers are asking clinical and mental health service providers to remember and believe '*We care so deeply*'.

It is intended that this booklet serves as a discussion point for families and carers as they traverse the healthcare system and services, shoulder to shoulder with the person they care about. It is hoped that it is a basis for deeper listening to ideas and advice that can make a huge difference in the recovery process.

Thank you for taking the time to read this and we hope it gives you a deeper understanding of the vital role families and carers play in supporting recovery.

Yours sincerely

Amanda Trunley

Chair, Greater South Joint
Mental Health Collaborative



Family engagement and support framework

This is the Family Engagement and Support Framework developed through a research project aimed at highlighting important areas of change needed for families and carers involved in mental health recovery.

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Domain one

Access to services and supports for the person

Gaining access to services for the person with mental health difficulties when required is a critical concern of families and carers. Consultations revealed that families and carers are feeling the constriction of services and many feel frustrated and abandoned.

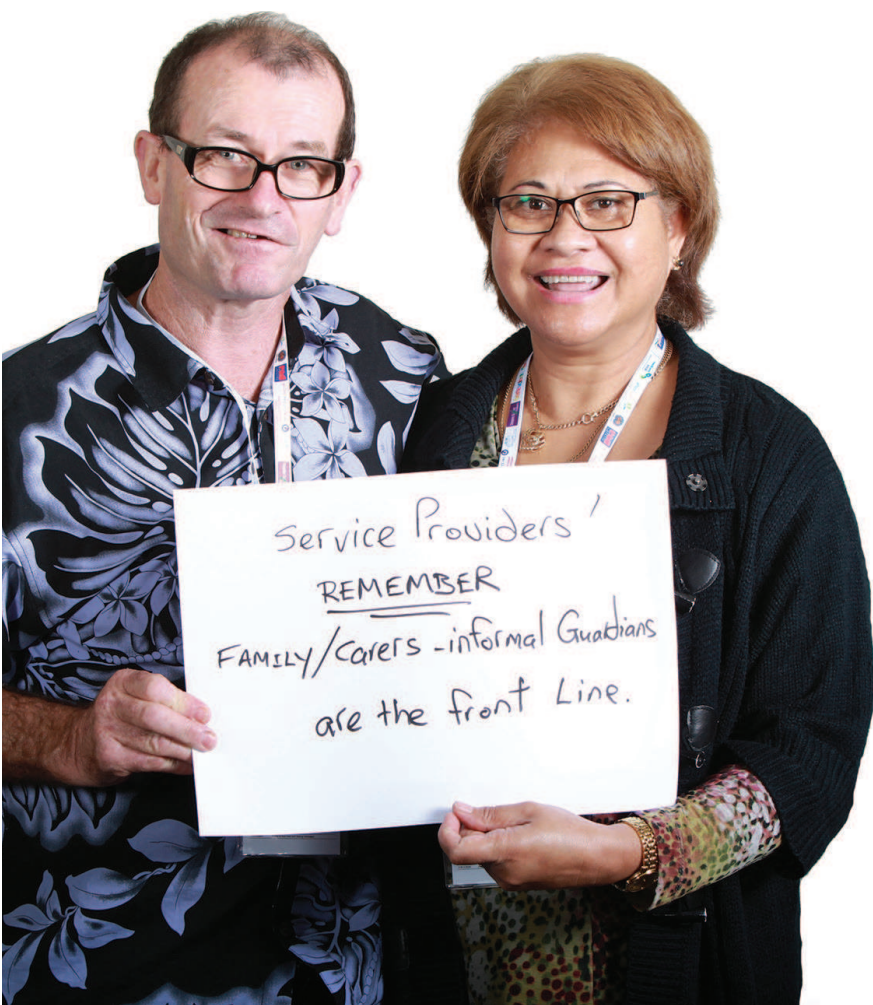
Families identified difficulty in gaining support for their loved ones especially when the person's distress is escalating.

Domain two

Partners in service delivery and recovery

Families and carers frequently feel disrespected and excluded from the care, support and treatment decisions of their loved one.

They feel that their contribution to the care and support of the family member is too often not acknowledged and their wisdom and understanding of the family member is not valued. People can even feel belittled and that their knowledge is seen as less important.





Domain three

Access to information and education to enhance the family's capacity to support the person

Many families and carers are poorly equipped to support the person with mental health difficulties and find it difficult to gain information and education that is accessible and targeted to their needs. Many recounted stories of struggling to get basic information about a range of topics both mental health-specific and practical. Sometimes families and carers don't know where to look for information about help for themselves.

Domain four

Support to sustain the health and wellbeing of family and other natural supports

The wellbeing of family and natural support network members who are supporting a person with mental health difficulties may be highly compromised. Families and carers must be recognised as being at significant risk of entering the mental health system in their own right unless there is adequate attention to their needs.

Some groups are likely to be at an even higher risk including Aboriginal and Torres Strait Islander peoples, refugees, young family members and those with multiple caring roles.



Important principles

When families and carers feel involved and included in the recovery process, it is usually because the following important principles are at play:

- respect for and understanding of the role of families and carers in a person's wellbeing, recovery and continuity of care
- rights to information, involvement, collaborative planning, support and recognition manifest in practical ways
- services and assistance are provided in a warm, honest, consistent and caring way
- families and carers are connected with each other, with support and the broader community
- services are coordinated and integrated.



When things are going well

- There is collaboration and involvement between families, carers and services.
- Different services are linked together.
- GP Mental Health Plans are in place.
- Recovery Action Plans are holistic and inclusive.
- There is hopefulness about the future when families and carers are:
 - in the picture and work together with practitioners
 - included in meetings and feel heard and respected
 - helped to navigate the system
 - supported and get the information they need
 - receiving warm and active referrals, rather than passive or reactive referrals

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The impacts on families and carers

- Families and carers can face many challenges.
- Seeing someone they care about experiencing mental health difficulties can cause confusion, sadness and anxiety.
- The process of caring can be costly in terms of time and money, and sometimes it is hard to make ends meet.
- This often impacts on the capacity to work and fulfil other responsibilities.
- Siblings can also be affected and may feel they have needs that aren't met.
- Families and carers need time to do things they need to do, to look after themselves and do things they enjoy. 'We need time together to strengthen bonds and relationships ... to be a mum or dad, sister, friend.'

What families and carers say

Check with families and carers if they know about entitlements that can help. Provide information through Centrelink.

- Link us with peer support groups.
- Link us with support agencies with a focus on families and carers.
- Understand it can be challenging and ask how it is going.
- Support us to be aware of our own health and wellbeing.
- Troubleshoot challenging problems with us if we ask for help.

Accessing services

Families and carers are often trying to work across many services and parts of the service system trying to get the help that we need. Having to knock on many doors and retell our story many times all make progress much harder, more costly and sometimes confusing.

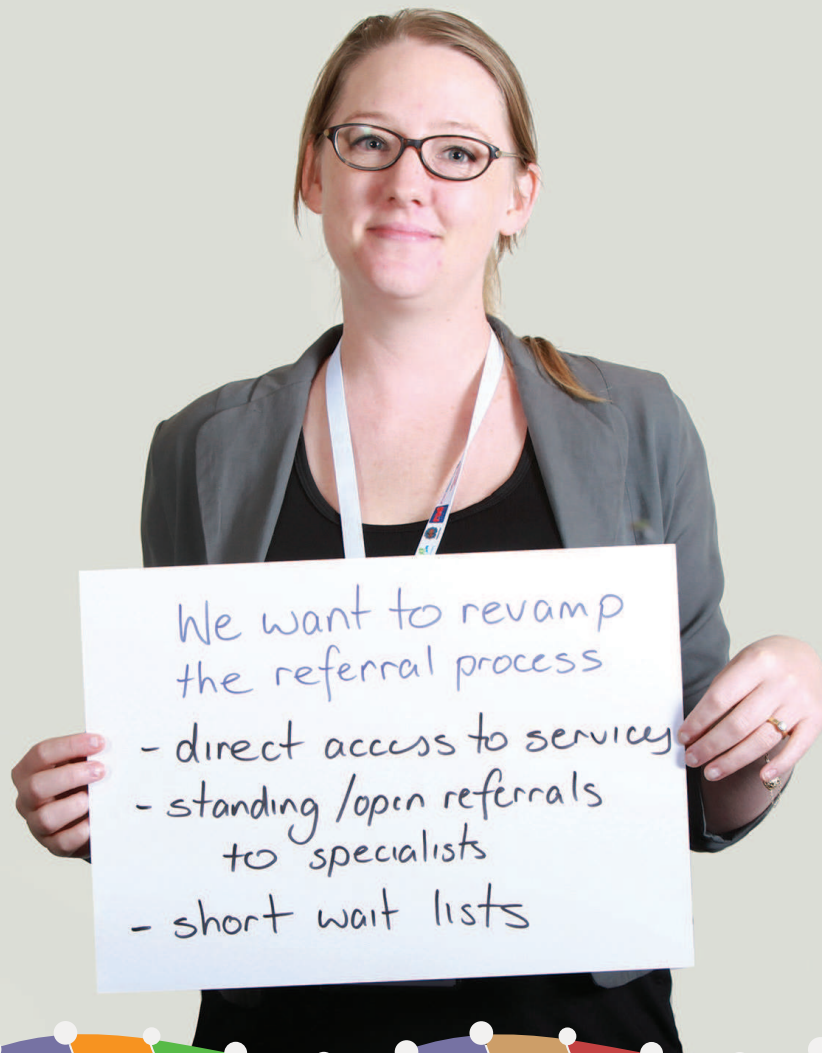
We need better access to services and to make progress in navigating the system wherever we knock on a door. We are essential to discharge planning and want to work with care providers on shared goals. What we say can make a real difference.



What families and carers say

When you meet families and carers these things can really help:

- provide information about what help is available
- actively refer families and carers to other people and places which might be helpful
- offer linkages and networks with other families and carers
- include a plan for addressing the needs of families and carers in the overall recovery action plan
- involve families and carers in discharge planning.



Better services

Families and carers can often see ways that could make the system better.

Some suggestions include:

- having access to outreach services at home
- flexible after hours support
- family and carer hubs, and space for family and carers in acute facilities
- joint family and carer meetings involving services and the person living with a mental health difficulty
- more access to direct support and education programs
- improved access to clinical services.



Information makes all the difference

It is so important to respect the rights of a person living with a mental health difficulty, yet families and carers can't help if we are left out of the picture. Families and carers also know it makes a real difference if the services involved in providing care, share information and communicate with each other.

There is a better chance that the various services someone needs will work together so the person will not fall through the cracks. A lot of energy by families and carers is spent trying to understand what is going on so we can help in the best way possible.

We often have to do a lot of work to stitch together different types of help. It can take away from our resources, energy and capacity to keep going.

It helps a lot when:

- service providers can talk to us and talk to each other!
- service providers get consent from everyone involved for communication to happen.



Working together

Families and carers are sometimes left out of the picture when it comes to information and plans for the future.

We want service providers to talk to each other and work in a coordinated way so our role is easier.

We hope for a way of discussing consent with the person living with a mental health difficulty which enables care providers to include families and carers when it comes to sharing information and planning for the future.

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What families and carers say

- Work with people to get their informed consent for a collaborative approach to sharing information and planning for the future with families and carers. This includes working with everyone involved to have family meetings to work things out together.
- Strengthen the role of GPs in a coordinated mental health plan which includes protocols for sharing information.
- Help us understand more about how the person is feeling so we can help.
- Recognise that we have experience, knowledge, expertise and history which can help with recovery planning. Recognise that we can make a big difference to the continuity of care.



Helping us get what we need

People often require responses to various challenges and goals. This may involve several agencies which may also change over time. It can be hard to navigate and make contact with busy services and contact may not happen the first time.

There is a difference between passive referrals (giving contact information) and active referrals. Active referrals usually involve contacting the other agency and making an introduction, explaining the situation and making sure the agency can assist (either in terms of role, eligibility or capacity).

The person referring can often help the referral to be successful by putting forward information, the strengths and needs of a situation, and enabling the destination agency to understand the situation as much as possible. Warm referrals help to welcome the person in such a way that they are less likely to lose contact.

This is all based on robust informed consent from the person, their family and carers. It can help harness the networks of service providers and help avoid a situation where contact is unsuccessful.

Sometimes assistance to coordinate and navigate complex systems is also important. This includes people whose role it is to help people pull together the things they need, when they need them. This is also an assertive process of weaving together complementary resources and services so that the system can deliver an holistic response.

Source: Adapted from Communities for Children Operational Guidelines, September 2014, Australian Government Department of Social Services.



What families and carers say

- Help families and carers by making direct contact with a service you are referring them to. With their consent, provide an introduction to make sure the service is in a position to help.
- When a situation is very complex, consider linking the person, their family and carer with services that play a coordination and linking role.
- Follow up and ask how the referral went. Offer to help if the connection isn't going well or could be stronger.

Early support

Families and carers are often the first people to notice a change or something that might indicate the person they care about needs more assistance.

Getting help as quickly as possible can reduce the risk of longer periods of acute illness and of families and carers feeling alone and unsupported.

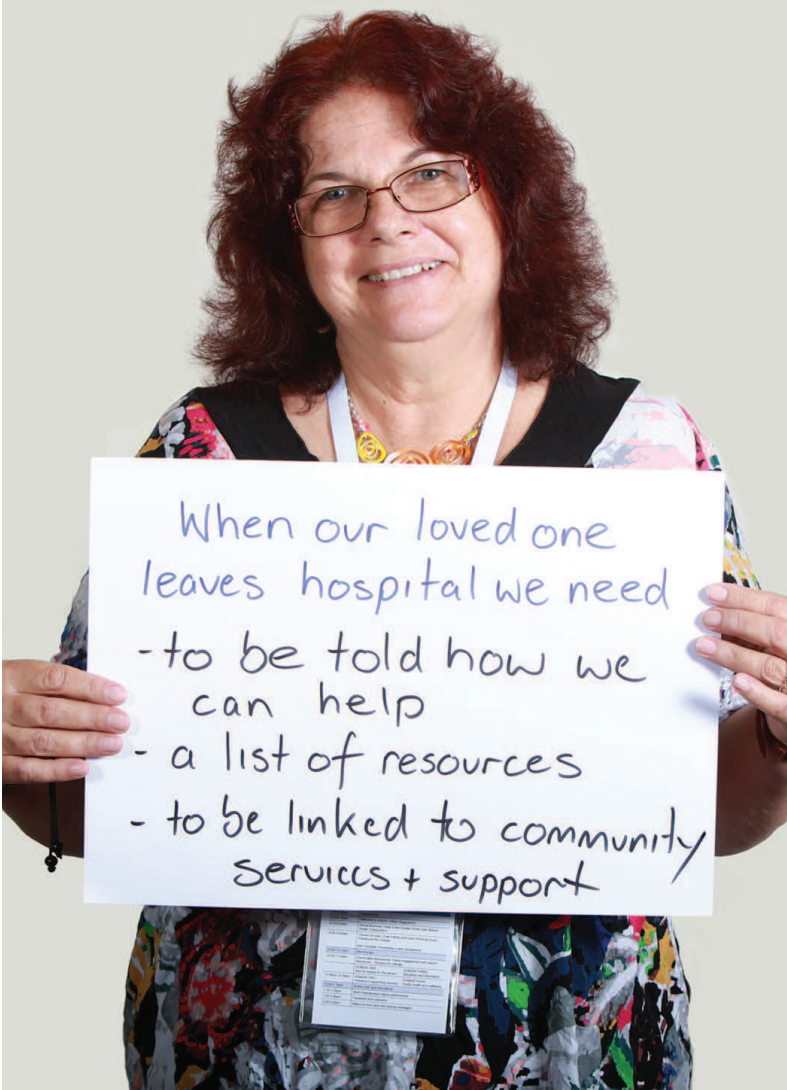
Being able to work quickly with health care providers can reduce periods of acute illness, prevent hospitalisations and preserve valuable support networks.

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What families and carers say

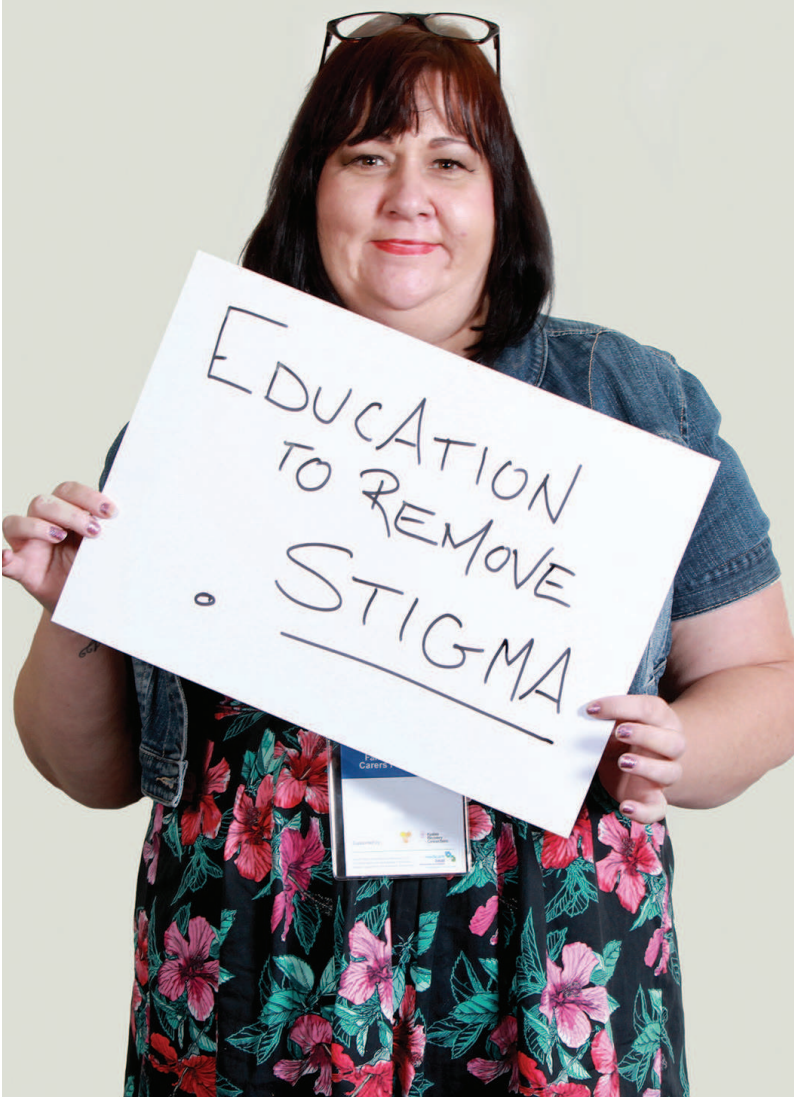
- Recognise that this is a stressful, difficult time and that families and carers need a supportive approach to help work out what to do to make things better.
- Meet with the person and their family as soon as possible.
- Help to actively navigate other support where needed.
- Respect the importance of natural helping community networks.
- Help identify challenges and work out solutions.
- If hospital is needed, work together towards discharge so there is a smooth transition.
- Provide post-discharge follow up.



Community support and education

Families and carers gain a lot from education about mental health issues and wellbeing and our role in recovery. It is a way of helping us to understand what is happening for the person we care about, and what recovery involves.

We also live in the broader community. It is here where there can be barriers to feeling supported and included because there is stigma and a lack of understanding. Families and carers need access to education for themselves. They also benefit a lot from broader community education campaigns which reduce stigma and increase understanding.



What families and carers say

- Encouraging and participating in education campaigns for communities and businesses. These should include people living with mental health difficulty and their families and carers.
- Actively linking families and carers with education programs about mental health difficulties, supporting recovery and maintaining our own wellbeing.
- Involve and engage schools in mental health education.
- *'We know when people hear our stories it can make a difference!'*



Preparing for the future

One thing that is often a concern for families and carers is how the future will unfold and what will happen to the person they care about if they are no longer able to do as much.

Future planning might be focused on a person moving out of the family home and into more independent living arrangements. It might be planning for a future with more supports from other services as a way of managing transitions

and life stage changes in the lives of families and carers.

Future planning can help families and carers feel more confident about what lies ahead and more at ease knowing that the person they care about will be OK. It can make a big difference to families and carers to be supported as they look to the future and what changes might be needed.

What families and carers say

- Create opportunities to talk about change and future planning.
- When a significant change is needed or preferred, help us plan in a more detailed way.
- Make sure we have access to support for ourselves if we need it.
- Show us you understand change is hard and that we are still doing a great job even though things need to be different.

Stories of hope

One of the most important messages that families and carers want to communicate is one of hopefulness. The following direct quotes highlight the importance of hope in recovery including the family and carers' recovery.

"Hi, I am a carer and I believe we need to be heard."

'... I recall witnessing a simple act in our home. To others it may not have registered as significant ... But it filled my heart with hope. An immense hope for my loved one to be experiencing feelings of safety and stability, in that moment ... Being present in the life of someone experiencing mental health difficulties can be intense, and these fleeting moments can go unnoticed. Moments visible through love, that are reminders of hope, and that a greater sense of ease in life and being in the world is possible.' Elizabeth

'... I remember the exact but unlikely moment that I was instilled with hope. My loved one was amidst a mental health crisis. Extreme distress. The nurse who received us in the emergency department recognised us from another day, at another hospital where she had noticed we were in need of mental health assistance. I could hear the concern in her voice, that we had not received the help we needed, despite seeking it. That was a long time ago, and there have been many ups and downs along the way. But it was in that moment that I knew we were not alone in trying to manage complex mental health difficulties. There was help on the way.' Carmen

'When my daughter was first diagnosed I felt like I was in a giant pit with no way out. The road to recovery is not an easy path to travel. Acknowledging this and moving forward with her recovery has also been a journey of recovery for myself. Seeing her acknowledge and manage her illness has shown me there is a way out of the pit. The struggles are always there but knowing that these will pass makes it a little more bearable. Joining a group with people with similar issues and doing a few courses has also given me the tools and confidence to be a carer.' Toni

"We as carers are experts in our field and that should be respected."

"Hi, I am a carer and I have made changes ... 'it is possible with help'."

"Be strong and be resilient."

"I believe we can make a difference."

"Education and information are powerful."

For more information

You can find
out more
information and
links here

The Greater South Joint Mental Health Collaborative:

Vicky Jacobson (Service Integration Coordinator)
Resource and Access Services Academic Clinical Unit
Metro South Addiction and Mental Health Services

Metro South Health T: 07 3176 1092

E: smhcollaborative@gmail.com

W: www.smhc.org.au

Carers Queensland Carer Information Line: 1800 242 636

ARAFMI Queensland: 1800 35 1881 (24 hours)

Lifeline 24 hour telephone helpline: 13 11 14

Suicide Callback Service: 1300 659 467 (24 hours)

Call 13 Health: 13 43 25 84 (24 hours)

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