

Self Empowerment Activities for Emotional Health

Guide for caregivers of
persons with Special Needs



ENRICH Project
Bangalore | June 2023

Disclaimer

The book “Self-Empowerment Activities for Emotional Health” is a Guide for caregivers of persons with special needs. This book includes caregiver guidance and health practices recommended by international bodies such as UNICEF and WHO. The content of this book is for informational purposes only and is not intended to diagnose, treat, cure, or prevent any condition or disease. This publication is meant as a source of valuable information for the reader, however it is not meant as a substitute for direct expert assistance. If such a level of assistance is required, the services of a competent licensed professional should be sought.

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Self Empowerment Activities for Emotional Health

Guide for caregivers of
persons with Special Needs

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ENRICH PROJECT

The Association for the Mentally Challenged, Bangalore
June 2023

Acknowledgements

We are thankful to all the persons with special needs and their families of The Association for the Mentally Challenged, Bangalore, for sharing their life experiences and joining hands in developing the self-care interventions. They have been a source of inspiration to the ENRICH Team in developing the interventional modules.

The funding for the ENRICH Project came from the Foundation Juan Jose Lopez-Ibor, Madrid. Professor R. Srinivasa Murthy was awarded the International Juan Jose Lopez Ibor award 2012.

‘The prize recognises initiatives in favour of the human dignity of those who suffer from mental disorders carried out from a scientific perspective. Bridging rational thinking and respect towards those who suffer mental illnesses is the goal of the Award’.

The award amount of Euro 40,000/ awarded to Prof. R. Srinivasa Murthy, was donated to AMC. These funds were utilized for the ENRICH project.

Our sincere thanks to the professional colleagues and caregivers who have reviewed the draft versions and provided valuable suggestions (Complete list in Appendix 3)

The design and layout was developed by Venkatesh Bilvam from Whitespace35, illustrations by Nikhila Arun, with content editing and proof-reading by Prachi Agarwal.

Dedication

To millions of persons with special needs and their families.

Families in India represent the best of Indian Culture in providing unstinted commitment, support and care to their family member(s) with special needs.

Community Speak

**This will definitely
prove to be invaluable
to all those working in
the field of disability.**

Prof. Priti Arun, GCMH,
Chandigarh.

**I already find them
robust, simple and
engaging.**

Dr. Vandana Gopikumar,
Banyan, Chennai

**A proactive step to
empowering carers
of parents with
children with special
needs. Self-Care
being the focus of the
modules is excellent.**

Prof. Srikala Bharath, (Retd)
NIMHANS, Bangalore

Your documents are wonderfully written in simple language. This would be very useful to people.

Prof. Rajesh Sagar, AIIMS,
New Delhi

Absolutely happy to support an important and meaningful project.

Dr. Meena Vythilingam,
Psychiatrist, Washington,
USA.

I am really glad to see such a project happening for catering to the needs of caregivers

Dr. Sangeetha Shyam,
New Delhi

I think it is easy and simple for people to understand. Mental health I guess is the most important need of the hour.

Ms. Chitra Shah, ASHA,
Puducherry

Introduction

In India, millions of persons with special needs with intellectual developmental disabilities and autism spectrum disorder are living with their families. Families in India represent the best of Indian Culture in providing unstinted commitment, support and care to their family member(s) with special needs. Caregiving is both emotionally fulfilling and challenging. This guide address ways to strengthen caregivers.

What are the needs? What are the Challenges?

A 'special child' changes life for the caregivers. The World Federation for Mental Health (2014) observed:

'Caregivers are also less healthy than non-caregivers, and have more chronic illnesses like high blood pressure, heart disease, diabetes and arthritis than non-caregiving peers. They may also suffer from poorer immune function and exhaustion. They may neglect their own care and have higher mortality rates than non-caregivers of the same age. Given these odds, caregivers need to take good care of themselves, and to reduce their level of stress, depression and anxiety.'

In the last one decade there are major initiatives to address this need of caregivers: In USA in 2017, **Family Caregivers Act 2017** was passed. The Act RAISE, calls for Recognition, Assistance, Inclusion, Support and Engagement of family caregivers.

The UNICEF has a new programme 'Caring for the Caregivers'

The Division of Mental Health of World Health organisation(WHO) is implementing a 30 country programme on **Caregivers Skills Training Programme** from this year.

As part of this 15 session programme, in the last session there is full acknowledgement of the importance of emotional health of caregivers and their need to take care of their physical and emotional health as follows:

It is very important to find ways to care for yourself too. It may be very difficult to find ways to care for oneself when caregivers have limited money or time, but this is so important for the entire family. Caregivers can protect their mental and physical health by caring for themselves the best they can. Caregivers who take care of themselves may have more energy to take care of others. If we have better well-being, it will be easier to cope when there are unexpected difficult situations.

Ways to practice self-care

It is important that you are kind to yourself and set small goals for caring for yourself.

Here are some ideas about ways to practise self-care:

- Trying to eat regularly and eating the healthiest foods we can is likely to be helpful for both our bodies and minds.
- Sleep is important in maintaining our energy, and the amount of sleep we get can also have an impact on our stress and emotions.
- Physical exercise can also reduce stress and improve our health and mental wellbeing.
- Feeling connected to other people and supported by them is very important for well-being. Sometimes, in order to stay connected, it is important to reach out to people around us.
- Spending some time on pleasant activities – such as meeting with friends and family, reading, taking a walk or listening to music – can help us to cope with stress and regain energy.
- Doing things that are important to us, such as religious practices, or belonging to a group or organization, can also help our well-being.
- We can also care for ourselves by practising acceptance. This means that we acknowledge our situation, and we stop fighting against things we cannot change.
- Acceptance does not mean that we like the situation, or that we want things to be how they are.
- Being kind and understanding towards ourselves is also important. We should try to speak to ourselves with kindness, like we would speak to a good friend, especially when we are having difficulties.
- It's also important to get help from a nurse or other professional, like Rosa did, when needed.

On the occasion of the World Mental Health Day, October 10, 2022, Ms. Deepika Padukone, actress and mental health advocate, shared her thoughts about caregiving as follows on NDTV.

Interviewer:

Deepika, we see we see your family traveling with you ... how important is the family's role when it comes to dealing with mental health?

Deepika Padukone

"Oh, it's extremely crucial, I mean even in my own personal journey, the role of the caregiver has been extremely important. That is why my mother's here with us today, that's why my sister is so passionately been a part of the cause for many years. When I hear the stories of caregivers, I understand how important are caregivers. The emotional well-being of a caregiver is as important as the emotional well-being of the person....I think caregivers in general whether it is mental illness or any other form of illness, it takes a toll on a caregiver and I think this district in particular, we seem to be focusing on that a lot more. We have programs where once a month all the carers come together, they form a group, they share their stories and their thoughts and their ideas and they feel like a community. They don't feel like they're alone and I think not feeling alone is such a huge part of this issue, because we all suffer in silence.We're all struggling in silence and I think a large part of what we're trying to do here is bring the community together, the community of people with mental illness but also the community of caregivers, bring them together to share each other's stories and know that you're not alone and that we're all in this together."

The 'ENRICH Project' has taken these self-care ideas to fuller development, especially for Indian families.

In the last decade, there is growing evidence to support self care activities for emotional health, along with lived-in experiences of caregivers.

The goal of the project is EMPOWERING families to fulfill their NEEDS and REBUILD families through INFORMATION, and SKILLS of CAREGIVING towards HOLISTIC DEVELOPMENT OF THE FAMILIES of DD (ENRICH)(2021-2022)

As a first step, during 2021, all the parents were interviewed, to understand their caregiver journey (Loss, Love and Growth document). They were assessed for their current emotional health using the W.H.O. Self-Reporting Questionnaire (WHO-SRQ), Further their current health practices for self-care were collected. WHO-SRQ (Appendix 2) is a easy assessment tool for knowing emotional distress at any one point of time. It can be used to periodically know the emotional health of caregivers. Positive scores of above 6 require greater effort at self-care and seeking of professional care.

In these individual assessments, more than half of the caregivers had scores suggesting poor emotional health. Most of them were not practicing the well established measures of self-care for emotional health. Draft interventional materials were shared for review and suggestions with over 30 health professionals and caregivers and their suggestions incorporated in the final version of the Guide. (Appendix 3)

A one day (6 hours) intervention programme with over 10 videos of about 5 minutes each were developed in Kannada and English. During 2022, 10 one day workshops for groups of 6-10 caregivers were conducted to share the self-care skills for emotional health.

This Guide presents two sets of skills for caregivers towards the self-care for emotional health. First set has 5 skills to become healthy and live long) (Modules 1-5). The second set of 5 skills to address emotional distress at the personal level (Modules 6-10).The above set of 10 activities will meet most of the day to day caregivers emotional health needs.

However, there will be need in some situations for professional services. The Guide includes guidelines for seeking professional help (Module 11).

Appendix 1 contains resources for further reading.

Foreword

The Association for the Mentally Challenged, Bangalore, popularly known as AMC, is the second oldest special needs organization in the country. AMC was started by Prof.D.L.N.Murthy Rao, of Mental Hospital. Bangalore in 1962. He authored some of the first scientific papers on special needs in the country.

AMC has been in the forefront of innovations for the care of persons with developmental disabilities and their families. ENRICH (EMPOWERING families to fulfil their NEEDS and REBUILD families through INFORMATION, and SKILLS of CAREGIVING towards HOLISTIC DEVELOPMENT OF THE FAMILIES) is in line with this leadership activities of AMC.

Persons with developmental disabilities, require three S's for their growth and development. These are Services, Support and Strengthening of family.

SERVICES indicate the needs from birth till the end of life. These needs are for early identification, early intervention, inclusive education, special education, continuous medical care, aids and appliances, support to families in the caregiving skills, day care facilities, prevocational and vocational training, sheltered workshops, residential care for those without families.

SUPPORTS are essential as persons with special needs cannot compete in the general community. Specific supports needed are increasing community awareness of the rights of persons with special needs, prevention activities as part of health services, financial support(monthly 'pension'), medical insurance(eg. NIRAMAYA SCHEME), bus pass, loan Facilities, housing support, income tax benefits, legal aid, and employment reservation.

STRENGTHENING THE FAMILY is vital in the Indian context as majority of the persons with special needs live with families. Supports needed are caregiving skills, crisis support, self-care for physical and emotional health and support groups of families.

The Self Care Guide addresses the caregivers physical and emotional health. The special nature of the guide is the bringing together the best of the currently known knowledge in the area of self-care and to adopt it to meet the needs of Indian population. There are videos to support the guide.

Currently the guide is available in Kannada and English. AMC is working together voluntary organisations and professionals to develop and disseminate the guides in all Indian languages.

I am deeply grateful to the Foundation Juan Jose Lopez-Ibor, Madrid and Professor R. Srinivasa Murthy, particular, who was awarded the International Juan Jose Lopez Ibor award 2012 . Prof Murthy has been the moving spirit and exemplar of Project Enrich. He has provided financial support for the project by donating the prize money to AMC, motivating and guiding Ms.Divya and Ms.Nischitha to make self-care package a reality. My sincere appreciation to the ENRICH Team. My colleagues in the AMC have extended admirable support to this Project- Kalpana, Meera, Srikanth, Maya, Vani, Ramdas, Pratima, Kichu, Hegde, Priya and Shekar. We have recieved support from Raghu and Manju, BPAC.

I am hopeful that this will be a milestone in the care of persons with special needs in the country.

K.Jairaj,
President, AMC

About AMC

The Association for the Mentally Challenged (AMC) was started in 1960 by Dr. D. L.N. Murthy Rao, then Director of All India Institute of Mental Health, Bangalore (now NIMHANS). AMC is a one-of-a-kind institution providing lifelong support for 120 – 140 individuals with Developmental Disability Disorders (DD). AMC is working with the goal to improve the quality of life of persons with developmental disabilities and their families. The wide range of services offered at AMC are provided free of charge, as 90% of the beneficiaries are from low socio-economic background.

Mission:

To promote development, independence, economic sufficiency, community inclusion, self-determination of persons with IDD.

Empowerment of their families through coordinated services of training, research, technical assistance and dissemination activities.

AMC has the following facilities:

- **Special school** for children with IDD. Besides classroom instruction, lifeskill training, the school activities include training in yoga, sports and various art forms.
- **Multi-category vocational training centre** trains adolescents and adults with IDD in weaving, candle making, pottery, carpentry and making paper products. The effort here is to identify their abilities and strengthen further to make them economically productive.
- **Sheltered workshop** which offers gainful employment to the trainees who are able to carry on the activities without much supervision. Recognising the difficulty for these persons to enter the mainstream job market, AMC is providing a protected and supportive work environment to help them discover a life that is self-governing. They get to take home a small amount of stipend/incentive every month.
- **Day Care Centre** for the severely affected engages the adults with severe issues with various activities through the day.

- **SAMRUDHHI**, a model programme of lifelong support to families of those with DD. Periodic counseling sessions by psychiatrists, psychologists and social workers provide comprehensive assessment and guidance. Monitoring and ensuring that the families avail the benefits of the various Govt. schemes for the special individuals, training the mothers of beneficiaries in various vocations and making them job ready are some of the initiatives under this programme. A parent's Self Help Group provides the perfect platform for an active engagement among the parents of beneficiaries and exchange of knowledge.
- **Clinic:** A multidisciplinary team from NIMHANS visits AMC periodically to provide medical care to the beneficiaries of AMC.

The other services provided without any cost to the beneficiaries include

- Supply of Uniforms, Shoes, Bags
- Serving Milk with multi millet porridge, vitamin supplements
- Nutritious lunch everyday
- Transport facility for everyday commute
- Outdoor activities like visit to exhibitions, fairs, picnic, etc.
- Yoga Practice & Training in Painting, Dance and Music

AMC is certified by Credibility Alliance and is recognised as Tier 1 NGO by Give India. It is also listed on Guide Star and India Cares. AMC was awarded The Best Institution by His Excellency the Governor of Karnataka and by Rotary for its excellent service to the society in 2009.

Shri. K. Jairaj, IAS (Retd.) offers leadership as the President of the AMC Committee. The office bearers, members of the Managing Committee, Staff, Volunteers, Donors and Parents of beneficiaries have been contributing significantly towards building this institution and continue to work selflessly.

AMC depends on support from individual donors and corporates in leading these initiatives. There is no aid from the Government other than support towards one teacher's salary.

MODULE 01

EXERCISE

Make a Wise Choice & Exercise

While looking after a person with special needs, you need to take care of your own health. Do you often feel stressed or anxious?

Well, working out is a way out.





Why is Exercise Important

- » Exercise is a good way to improve emotional well-being and physical health.
- » Exercise helps people live longer.
- » Exercise improves the effectiveness of treatment of conditions like high blood pressure, diabetes, and other chronic illnesses.

?

Did you know?

In Japan, exercise is popularly known as “Forest Bathing” which means spending time in the parks, gardens, and forests.



?

Did you know?

Exercise is an essential part in the treatment of depression. 16 weeks of exercise is similar to mild-to-moderate doses of anti-depressants. 3 days of exercise every week can reduce symptoms of depression by 20%.

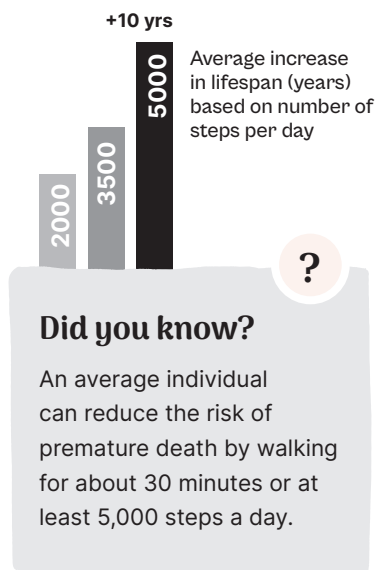
Understanding Exercise

Physical activity has been an essential part of our lives until recently, when most of us have started leading a sedentary life. In other words, suffering from the sitting disease.

This inactive lifestyle is actively contributing to poor health conditions such as obesity, diabetes, hypertension, and cancer. It is also causing mental distress in the form of anxiety and depression.

How does Exercise Help?

- » Walking, running, workouts, and dance lead to better physical as well as emotional health, improving your overall quality of life.
- » During exercise, your body releases endorphins that help reduce stress and improve sense of well-being.
- » People who exercise regularly live at least 10 years longer.
- » It lowers the risk of heart disease and strengthens immunity.



Tip

It might be difficult to motivate yourself to exercise after having a stressful day. However just 15 to 30 minutes of any kind of workout will help you feel better.

- » It is helpful in treating conditions such as hypertension, diabetes, and other chronic illnesses. Exercise is also considered medicine when it comes to treating chronic illnesses.
- » Those who exercise regularly have been more likely to recover from the COVID-19 infection faster.
- » Certain exercises help in reducing lower back pain.
- » Getting enough exercise helps in sleeping better.
(See **Module 2**)

10

Ways you can include **EXERCISE** into your daily routine



1

SPECIFIC SCHEDULE

Just like taking medicines, fix a specific time for exercise too.

2

SLOW AND STEADY

Start slowly and gradually increase the time to at least 30 minutes per day.

3

GREEN SPACES

Try to exercise in your garden or a nearby park.

4

FITNESS AND FRIENDS

Go for a walk with family members, neighbours, or join a community group.

5

MAKE IT FUN

Listen to the radio or your favourite music while walking.

6

FUN WEEKENDS

Use the weekend to become active with your family – go to the park and play games. You can also try jumping activities. Make it a fun time for all.



7

SUPER STAIRS

Take the stairs wherever possible.

8

SIT AND STRETCH

You can even stretch while seated with some basic hand and leg stretches.

9

TACKLE YOUR TENSION

While working continuously get up and move. Sitting for long hours can tense and strain muscles in your neck and shoulders. Be mindful and for ten minutes every hour stretch your neck and shoulders - move them up and down and rotate them around.

“

..feels like a miracle!

I was recently diagnosed with diabetes. I was shocked and scared. I am only 30 years old. Around the same time, I attended the parent workshop on self-care at AMC and learned that exercise will benefit my health. It inspired me to start walking every day without fail. In my next hospital visit after a month, my doctor said my sugar levels are coming under control along with taking medicines. This feels like a miracle.

Mrs. Parvathi,
Mother of a child with special needs.

10

MONITORING

Keep track of your physical and emotional health. You can maintain a chart of your weight and resting heart rate. For emotional health, you can also try the Self Reporting Questionnaires (SRQs). (See [Introduction](#))

Caregiver Stories

..feels refreshing..

Because of COVID-19, I had stopped going for walks and the practice just got discontinued. But after attending the workshop, I have resumed going on my morning walks. It feels very refreshing. If I am not able to go to the park, I walk around my locality or sometimes do yoga and meditation indoors.

Mr. Shankar,
Father of a child with special needs.

**..increased my
motivation..**

Rathna is a working mother of a 7-year-old child with special needs. She was finding it hard to focus on everything and at the end of the day was physically drained. On her doctor's advice, she started 20-30-minute-long evening walks. Some days she goes for a walk with her child in the park. She expressed that going for a walk and exercising has increased her motivation and improved her attitude toward work. She also feels less tired and completes her tasks on time. She enjoys spending time with her child while exercising.



MODULE 02

SLEEP

The Best Bridge Between Illness and Health

Research shows that family caregivers often have trouble sleeping, making them likely to develop physical and mental health problems.

As a parent, it is normal to worry about your child. Such worries can many times cause sleeplessness, which in turn may cause fatigue and even affect your health.



Why is Sleep Important?

- » Sleep is an important part of your daily routine.
- » Getting about 8 hours of sleep every day helps you in carrying out daily activities effectively. Otherwise, you may feel moody and emotionally volatile which can possibly affect your relationships.
- » Disturbed or inconsistent sleep can make you feel tired, affect clarity in thinking and attention-span, or cause physical problems.

Understanding Sleep

While asleep, our body undertakes a lot of repair activity and our subconscious mind consolidates our daily experiences (memory). It is the time when our body resets itself. This is why you feel fresh after a good night's sleep.

People with irregular work and sleep routines, such as factory workers, night shift workers, drivers, security guards, and nurses are more prone to health problems.

i

Did you know?

Sleep deprivation among drivers has been known to contribute to around 20% of road accidents.

**Making sleep a priority
will make you healthy and
a better person.**

You know how alcohol can silently affect our organs internally? Not getting adequate sleep even for one night can disturb you in various ways. It can lead to impaired concentration, memory, learning and decision-making.

It can also affect your appetite and make you feel tired, anxious, and irritable. Physically, lack of sleep is known to increase the risk of conditions such as obesity, stroke, diabetes, heart disease, and cancer.

How does Sleep Help?

- » Heals the body
- » Improves memory
- » Strengthens immunity
- » Boosts mood
- » Reduces stress
- » Sharpens attention
- » Lowers blood pressure and improves sugar control
- » Reduces the risk of depression
- » Enhances creativity
- » Decreases risk of cancer



..less irritated and angry..

I didn't know anything about a healthy lifestyle. After attending the parent workshop, I understood that sleeping about 8 hours will help me to be in a calm and pleasant mood in the morning. I have adopted the suggestion. It helped me in getting less irritated and angry.

Mrs. Manjula,
Mother of a child with special needs.

i

4 Reasons that Prevent You from Sleeping Better

Poor Health

Physical conditions or emotional distress. Feeling unwell or stressed can affect peaceful sleep.

Unfavourable Environment

Excessive light or noise, or unregulated temperatures. Using gadgets such as computers, phones, tablets, and TVs close to bedtime is bad for sleep.

Adverse Lifestyle

Eating sugary foods, drinking alcohol or late-night exercises. Some routines can contribute to poor sleep.

Major Life Events

Any unexpected changes in family or personal life, good or bad, can affect sleep.

9

Ways to get better **SLEEP**



1

RECOGNIZE

Sleep is as important as eating, exercising and relaxing.

2

SCHEDULE

Keep the same bedtime and wake-up time throughout the week, including weekends.

Regulating your body clock this way will improve the quality of sleep.

4

DAY AWAKE

Limit your day time sleep.

3

JOURNALING

Write down your thoughts and worries. (see Module 7)

Clear your mind of worries and try to calm yourself before going to sleep.

5

LIMIT HEAVY MEALS

Keep a 2-3 hour gap between dinner and bedtime.

6

BEDTIME RITUALS

Adopt activities to calm yourself such as taking a warm bath, drinking tea, or listening to soothing music. Switch off the lights.



7

SLEEPY SEVEN

Allocate a minimum of 7 to 8 hours for sleep.

8

LIMIT A-C-E

Limit Alcohol and Caffeine intake, and use of Electronics close to bedtime.

9

THE BODY SCAN

Focus your attention on your body parts and relax. (see Module 4)



MODULE 03

CONNECTEDNESS

Being Connected to Others
Strengthens You

Having a person with special needs in your family can induce feelings of guilt or shame, nudging you to avoid meeting others.

The person with special needs and their entire family, including you, need support and acceptance in this lifelong journey.



Why is Connectedness Important?

- » As human beings, we are social in nature and need to be connected with others.
- » Social connections improve emotional and physical health.
- » Being connected to others reduces stress and provides meaning and purpose to life.
- » Support from others minimizes the challenges of caregiving and provides opportunities for growth.

Understanding Connectedness

As a caregiver, you may at times feel lonely. So it is helpful to find support from others. Social connectedness develops early in our lives and remains with us throughout. You can experience the power of being connected to others. Think about your childhood. You were attached to your parents, who made you feel protected. While growing up, you connected with other people who had similar interests, and formed friendships that give mutual support.

When you don't have people to reach out for support in difficult situations, you can feel helpless and depressed. Building a network of people to support you can be very helpful. Connectedness with others can reduce your own burden.

In rural communities, it is generally easier for people to stay socially connected. In the urban context, however, you may have to make some effort. You can try to interact with others in your locality/community, share your feelings and experiences, or become a part of a social group. These can help you build a strong support system around yourself.

One of the important connections you can make is with other families caring for a person with special needs. There is so much that you can learn from each other by sharing experiences, supporting each other, and even using your collective force to bring in changes in the government policies.

How does Connectedness help?

- » It makes you feel heard and understood.
- » It encourages learning from others.
- » It assures you of getting help when needed.
- » It can provide collective strength to bring about changes.
- » It strengthens your sense of purpose.

All of us have family members and friends we try to stay in touch with. Among your family members and friends, who are the ones you want to stay connected with? You can try to develop a personal relationship with them. Share your feelings and seek help when you need it. Even within your locality or workplace, identify people or colleagues and share your experiences of caring for a child with special needs. You can also find professionals in your area and reach out to them whenever needed.

Your community can be a vital source of support. Community life helps to shape our identity and teaches us skills that help us to lead our lives. It can also enhance the quality of life and human experiences, as is evident from Jyothi's story.



..I feel less worried..

Jyothi is the mother of an 8-year-old child with special needs. She had been worried and lost for help. While searching for answers, she met another parent (Jaya) in school. They found a sense of relatedness and comfort with each other. Jyothi opened up about the diagnosis of her child, and Jaya helped her connect with other parents with similar difficulties. They listened to Jyothi and shared their experiences. Now she feels less worried as she has a support group that understands her struggles. This connectedness helped her plan a better future for her child.

No life is a waste. The only time we waste is the time we spend thinking we're alone.

8

Ways to stay

CONNECTED



1

RECOGNIZE

Your need to be connected to others.

2

DEVELOP

A special relationship with people close to you.

4

LISTEN

Without judgement.

3

SHARE

Your feelings regularly.

5

COMMUNICATE

Your own feelings and **Understand** theirs.

6

ACKNOWLEDGE

The support received and **Reciprocate**.



7

ASK

For help when you need it from others.

8

JOIN

hands for collective action.

9

CONNECT

with groups or people you identify with.

When you go to your child's school, for instance, try to interact with other parents. Feel free to share your feelings or express your fears. Slowly, you will find people understand you, respect your journey and are willing to support you.

Know that you are not alone in the journey of life. Talk to people you trust. Slowly you will start gaining courage and feeling strong in being connected.

MODULE 04

RELAXATION

An Art of Letting Go

Do you feel exhausted, irritable, unable to make decisions, experience body pains, or feel tired most of the day?

These symptoms indicate that your body needs to rest and relax.



Why is Relaxation Important?

- » Relaxation relieves stress, strengthens the immune system, and helps calm the mind.
- » Regular relaxation can be the road to a good day.

Your calm mind is the ultimate weapon against your challenges. The sensation of energy expands with increasing relaxation.

Understanding Relaxation

All of us have different capacities to handle the demands of our lives. You may feel stressed when you face a situation that is beyond your emotional or physical capacity. Stress however beneficial for short periods, can be harmful to the body and mind when it is excessive and continues over time.

Caregiving can at times, be challenging and cause emotional worries. As a caregiver, you have to deal with uncertainties almost on a daily basis. Relaxation will facilitate your mental well-being and help the body function better.

Worries and tension can be the starting point for many health problems.

It is important that you also take care of yourself while caring for your child with special needs.

Relaxation decreases the effect of stress on your body and mind. Many modern illnesses like diabetes, high blood pressure, and cancer are also associated with chronic stress. Therefore, relaxation also works as part of treatment of other such stress-related problems including heart disease, diabetes, asthma, depression, and anxiety.

Relaxation includes techniques such as deep breathing, yoga, meditation, focus breathing, and guided imagery. If you practice any of these techniques every day, they will lead to a more peaceful mind.

How does Relaxation help?

- » Daily practice of relaxation techniques reduces the effects of everyday stress.
- » Relaxation improves immunity.
- » Relaxation improves quality of sleep.
- » During COVID-19, those who practiced relaxation had positive recovery.
- » In case of serious illnesses, adding relaxation facilitates and enhances the effects of treatment.
- » Relaxation helps in managing depression and anxiety.

Sometimes letting things go is an act of far greater power than defending or hanging on.

Take rest; A field that has rested, gives bountiful crop.

”

..feel less tense..

Anu is a parent of a child with special needs. When the lockdown due to COVID-19 was announced, she got worried that her child wouldn't be able to go out and play. "During the lockdown, my son was showing hyperactive behaviors and was difficult to control," Anu shared with her friend Maya. Maya explained, *"You know this pandemic is temporary and everything will get solved. All you have to do is to practice methods of calming your body and mind, so that you can respond best to difficult situations"* Anu learnt deep breathing. It helped her. She now follows the relaxation technique and tries to make time every day to practice it. She also does yoga. With these changes, Anu "feels less tense," can "think creatively" to work with her child and handle household work and family responsibilities.

3

Ways you can make **RELAXATION** a part of your life



1

DEEP BREATHING

A stimulating breathing technique to renew your energy in the middle of the day.

- » Sit comfortably in a chair or on the floor.
- » Close your eyes and relax your body and muscles and the tension in your arms, legs, back and neck.
- » Inhale through your nose for as long as you can – you will feel your diaphragm and abdomen rise as your stomach moves inside. Now slowly exhale to a count of twenty - pushing out every breath of air from your lungs.
- » Repeat this five times. Do it twice a day.
- » After enough practice, you can increase the number.

2

YOGA ASANAS


Yoga is a well-recognised technique of relaxation. *Yoga asanas* provide the physical and mental balance needed to prevent stress and anxiety.

- » They help balance the nervous system and heal emotional pain.
- » Asanas require you to hold body postures for some time and the deep passive stretching will help you relax even more.
- » Practicing yoga can be the path to meditation practice.
- » There are many asanas and methods that can be learnt from professionals and practiced at home.



3

4-7-8 BREATHING

- » Sit comfortably with your back straight and move the tip of tongue behind your upper front teeth
 - » Exhale completely through your mouth, keeping the tongue in behind your teeth.
 - » Count to four, close your mouth and then inhale softly.
 - » Hold your breath while you count to seven and exhale through your mouth counting to eight.
 - » These steps comprise one breath of 4-7-8.
 - » Start over with the inhaling and repeat the steps three more times.
 - » After enough practice, you can increase the number.
- 

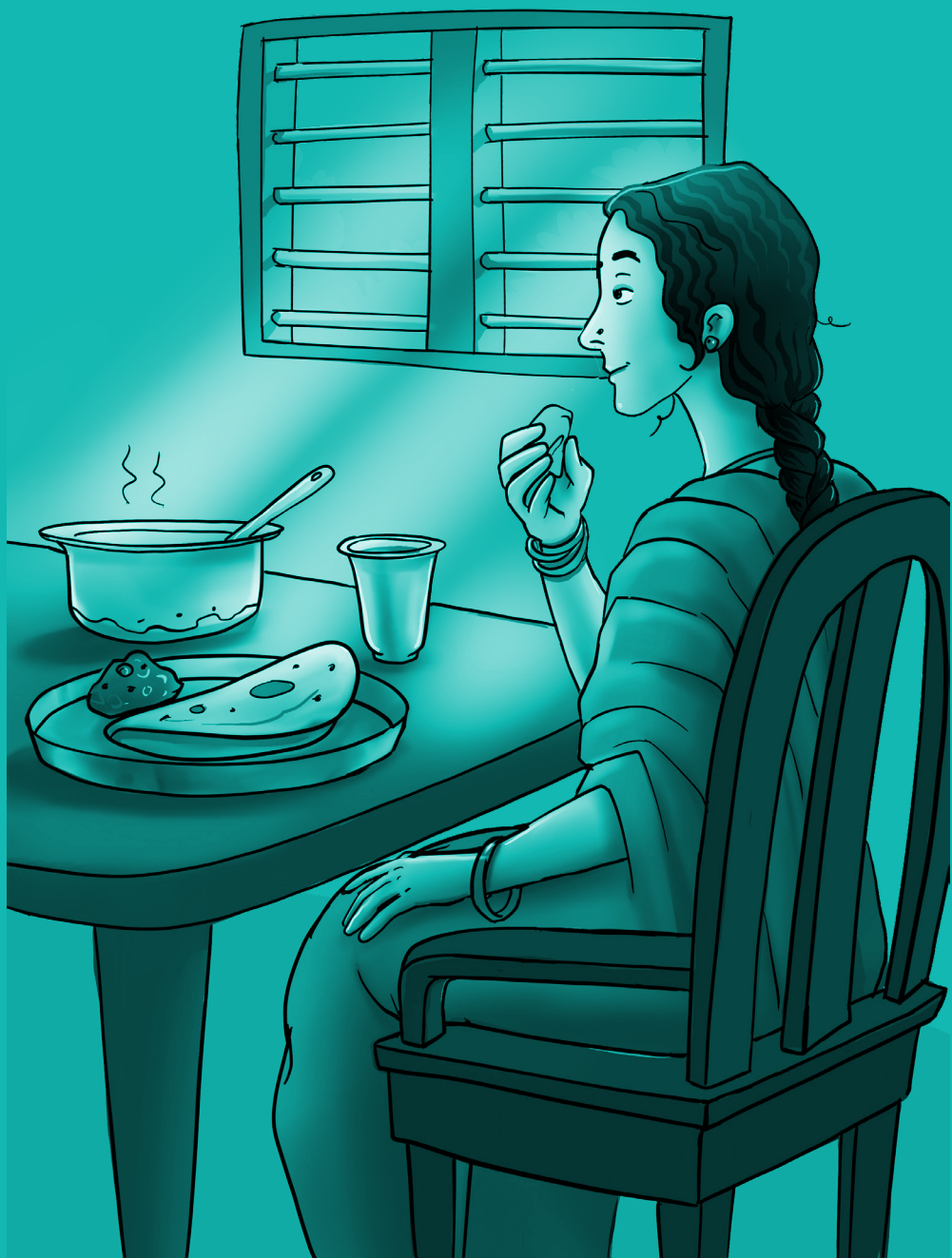
MODULE 05

NUTRITION

The Surest Way to Health

As a caregiver you may have irregular meal timings to be available for the ones you care for. You may often find yourself skipping meals or eating leftovers food. If this happens to you, you are neglecting your own nutrition needs.

The food you eat should be fresh.



Why is Nutrition Important?

- » All energy needed to by your body for various activities come from nutrients in your food.
- » Any deficiencies in nutrition can lead to health problems.

Enjoy eating and make it a healthy habit.

Understanding Nutrition

Paying attention to nutrition is one certain way to maintain health.

Ordinarily, a daily diet should consist of many components that are essential for the body such as carbohydrates, protein, vitamin, fats, minerals, fiber, and other micro-nutrients. In addition, such diet should avoid substances that can be harmful such as alcohol, drugs of abuse/chemicals, and pesticides.

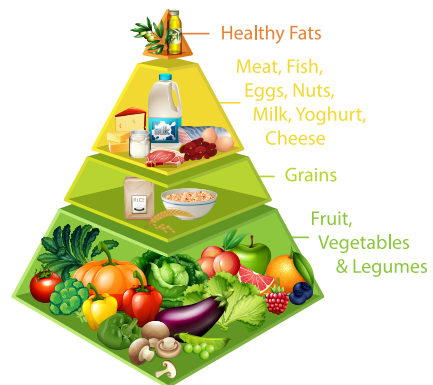
In the long-term, a balanced diet can improve your sense of well-being and emotional health.

Have you noticed that often when feeling stressed or even busy we tend to eat a lot of food (including packaged food) without thinking what we are eating.

While satisfying in the short-term, such food doesn't have the components of a balanced diet, and could lead to an unhealthy body and mind.

Without us realizing such poor nutritional habits can contribute to risks of high blood sugar, stress, tiredness at work, headache, affecting both heart and brain health.

HEALTHY EATING PYRAMID



How can Nutrition help?

- » Eating fruits daily reduces the risk of heart problems.
- » Drinking enough water and staying adequately hydrated will improve your concentration, and memory, especially as you get older.
- » Adding iron and vitamins in your diet will give you energy.
- » Eating protein-rich food will improve your immunity.
- » Having an overall balanced diet will help you abet depression and improve your cognition.



..much better physical health..

I work as a housekeeping and kitchen staff in a school. I started to experience body aches by the end of the day when I am back home.

I attended the workshop at AMC and observed that if I have my food in time, my physical health becomes much better.



Healthy food

- a. Sea-food, and meat
- b. Cooked food
- c. Wholegrains and soya products
- d. Fruits and nuts
- e. Vegetables including green leafy vegetables
- f. Legumes

Unhealthy food

- a. Processed, packed, and stored food
- b. Alcohol
- c. Excessive salt
- d. Products made of maida (all-purpose flour)
- e. Savory and candy snacks
- f. Burgers and fried food
- g. Red meat
- h. Sweetened beverages

10

Ways you can include **NUTRITION** into your daily diet

1

RAINBOW ON YOUR PLATE

When you set your plate and start eating, notice all the colours of different types of food on your plate. Try to ensure at least 1/3 of the plate is fruits and vegetables.

2

FRESH OVER FAST

Prefer eating fresh or freshly-cooked food over readymade or fast food.

3

GROCERY BY THE SEASON

Consider shopping for and eating seasonal fruits and vegetables. It will not only cut costs but also meet the body's nutrient requirements.

4

MINDFULNESS COOKING

How food is cooked on the stove decides how much nutrition we get on the plate. For example, there are benefits in slow and high temperature cooking, such as sautéing as compared to frying. Frying can be harmful as it promotes inflammation and can also affect mental health.

5

PREFER

Boiling, steaming, or baking food

6

PLAN AHEAD

To avoid eating unhealthy due to lack of time, it will be helpful to plan what you would like to eat and grocery shopping in advance.

7

FRIEND YOUR FIBER

As much as possible, try to build fiber into your meals. These can include whole fruits and vegetables, beans, legumes, and green leaves.

9

WATER RULES

Keep yourself hydrated through the day by drinking adequate amount of water - about 3 liters per day.

**Every time you eat or
drink, you are either
feeding disease or
fighting it.**

8

SPICE IT UP

Include spices like cinnamon (*dal-cheeni*), asafoetida (*hing*), cumin (*jeera*), and turmeric (*haldi*). These have medicinal benefits and adding them into food can help boost immunity.

10

PERIODIC FASTING

All communities practice fasting in different ways. Fasting is known to have its benefits and it rests our body functions. When appropriate and in a healthy manner, you can try to practice fasting too.



MODULE 06

SHARING FEELINGS

Asking for Help is a Sign of Strength,
Not Weakness

Did you ever think that caring for a child with special needs is like growing a plant in your garden? Just like the gardener, as a caregiver you experience many ups and downs throughout your caregiving journey.



Think about the process of growing a plant in your garden. Picking a sapling from the nursery and planting it in your garden alone will not make it grow. The plant will need care and nurturing. It will need the right amount of water, sunlight, and manure to grow wholesomely.

Sometimes despite doing a lot of things right, the plant might still wither, lose its charm, or stay delicate. At other times, the plant might just grow into its own

potential with minimal support. The role of a gardener, therefore, is to provide the plant with the necessary care to optimise its growth.

You may have many unexpressed feelings of sadness, helplessness, hopelessness, even triumph and gratitude. One way to deal with feelings of distress and effectively channel the positive feelings is to share these with people you are close to and trust.

Why is Sharing Feelings Important?

- » Sharing your feelings will help reduce stress.
- » It will make you feel heard and understood.
- » It will make you feel less lonely in the face of distress.
- » It helps in re-evaluating the situation.
- » You may discover a new perspective on the situation from the other person.

?

Did you know?

Sharing about your needs and experiences with other people will help you with your mental and emotional health.

Understanding Sharing Feelings

Based on events in the past or fears of the future, that build your perception and understanding of certain situations, you may find yourself feeling strong emotions.

One of these emotions can be distress, which understandably is very unpleasant and can affect the way you think and act. It can also limit your choice of response to the situation.

All of us experience distress at different points in our lives. As parents/caregivers of children with special needs, at various instances in your journey, you may feel worried, anxious, irritable, angry, frustrated, helpless or even hopeless. You may feel that things are not in your control. But you must know that these are all natural and part of the caregiving experience. However, it is difficult to reach out for professional help everytime you feel this way.

Generally, in families with person(s) with special needs only one person (mostly the mother or grandmother) takes up the caregiving responsibility.

“

relieved my distress..

During the support group meeting, I felt free to share. I get strength from listening to different parents' stories and their struggles. I was able to empathize with them. I shared my sadness and feelings with them. It relieved my distress.

This person can get so engrossed in caregiving, that (s) he can get disconnected from other people and activities of life.

Some common situations caregivers have shared as distressing are:

- 'Child not making progress in learning'
- 'Child not obeying'
- 'Child throwing temper tantrums'
- 'Others making fun of the person'
- 'Fear that who will look after the child when you are not there'

Holding on to such distress and keeping it to yourself is harmful. The mind of the person in distress is like a closed room filled with dust and bad smell. Opening a small window can let fresh air in, reduce the smell and bring in freshness. If as a caregiver, you are experiencing feelings of loss, fear, hopelessness and social stigma, you can find relief in letting someone in and sharing your feelings.

Finding a person you trust and opening up to them about how you feel and the things that are bothering you will offer relief. It is observed that as you share your distress, you get to see the different facets of the situation.

The other person may provide alternative ways of understanding or responding to the situation. Sharing is an act of self-care, not selfishness.

Sharing how you feel is a very valuable self-care practice.

..changed my life..

I was feeling ashamed about my child going to others' home and asking for food. One day, I decided to share the special needs of my son with my neighbours.

That conversation changed their understanding, and they reached out to help. This sharing changed my family life.

How does Sharing Feelings help?

- » Sharing your feelings helps to relieve emotional pain.
- » It builds connection with another individual and helps you feel understood.
- » It will help you realise that you are not the only one feeling distress.
- » It helps reduce stress and strengthen the immune system.



..helps me calm down

There were times when I go to my native place and talk about my misfortune to my brothers. They help me calm down by listening to me and offering ways to master the situations.

Mrs. Mary, mother of a child with special needs



..give me strength and inner peace..

I was really stressed about my child. I am generally very open about what is bothering me. And a lot of times I have shared my distress with my employer, my close friends, and anyone who is willing to listen to me, not with the intention of expecting any help, but just to have someone to hear me out. The opportunity of being heard is something that gives me strength and peace to move forward in life.

Mrs. Fathima,
mother of a child with special needs

**Shared joy is a double joy;
shared sorrow is half a
sorrow.**



Ways to

SHARE FEELINGS



1

IT-HAPPENED-WHEN

Identify the situations where you experience distress.

2

I-FEEL

Focus more on what you are feeling, rather than what happened.

3

I-NEED

Accept your vulnerability and the need for help/relief.

4

I-HAVE

Build a network of people with whom you can share your feelings.

5

I-WILL-ASK

Reach out whoever you want to talk with, either in-person or by phone. This could be a family member, a friend, or another parent with a child with special needs.

6

I-WILL-TALK-AND-LISTEN

Express your feelings openly and ask for help. Try to understand about how s(he) sees the situation.

7

I-AM-SAFE

Always choose a comfortable, secure and one-on-one environment to talk and share.

8

I-WILL-ACT

Develop a plan of action to address the situation, so you can avoid it from happening again.

9

I-WILL-TRY

Where you have no one to share with, use Journaling.
(see Module 7)



MODULE 07

JOURNALING

Not only Life-Changing,
but Life-Expanding

Life is a puzzle. You can only see the full picture when you put all the pieces together. Similarly, caregiving has a lot of parts. It is not only about caring for the child, but also about experiencing both negative and positive feelings. Acknowledging this wide range of experiences and emotions can improve emotional and physical health.



Why is Journaling Important?

- » It can help in understanding the daily personal experiences better and learn from them.
- » It brings clarity to thoughts and feelings and help in reflecting on situations more clearly.
- » It can make it easier to identify alternative ways of thinking about the situation.

**The power of writing
to heal is not in the pen
or paper, but it is in the
mind of the writer!**

Understanding Journaling

Caring for another family member can evoke both positive and negative feelings and emotions. Sometimes these can be overwhelming. As a caregiver, you live in demanding situations and your mind can be filled with recurring thoughts. You may feel like your mind is going round and round. Such situations can take a toll on your physical and emotional well-being.

In this caregiving journey, sometimes you will experience sadness, anger, failure, heartbreak, loss, or illness and at other times, feelings of fulfillment and success. There can be some feelings or events that are very intimate and difficult to share with others **(Module 6)** due to the fear of getting judged or being misunderstood.

Journaling is writing down your thoughts, feelings, and emotions without holding back. This is an opportunity to not only express but also record experiences.

Similar to sharing feelings, while writing also new understanding and insights regarding the situation will emerge. Writing also releases the emotions and thoughts associated with the event or situation. Journaling is an activity you do for yourself and whatever you write is limited to you. So you don't need to worry about grammar and sentence formations, as long as you can understand what you are writing.

How does Journaling help?

- » It reduces stress and improves health.
- » It will be your own record that you can use in the future for reference.
- » It helps identify the pattern of problems in your life.
- » It helps connect the dots and find the causes and effects of certain situation.
- » It increases self-awareness.
- » It helps translate thoughts and feelings into words.
- » It helps develop a plan to protect and maintain your energy.

Journal writing is the voyage to the interior.

You are stronger than you think.



Tip

There are three kinds of journals that can support you in times of distress or success:

Notebook or letter: –

Express what you feel by writing it in a notebook. You can write about any new things you learnt, or about the frustration that you are feeling or the positive experiences of the day. You can also write a letter of gratitude to God.

Draw and colour: You can use colours and express yourself without words. Or, you can draw pictures and diagrams to express your experiences.

Meditative writing: Writing the name of a deity, or religious verses helps calm the mind and body.

9 Ways to start JOURNALING

There are many ways of journaling. You can choose any method that works for you.

1

TIME TO JOURNAL

It is a good practice to keep a specific time in the day to journal. This could be early in the morning before starting the day, at night before going to bed, before or after you pray, or before or after your walk in the garden.

3

MAKE IT YOUR OWN

Buy a stationary item that you like such as a pencil, crayons, sticky notes or stickers. Make your journal decorative, colorful, or anything you would like.

5

TALK TO THE DIARY

Write down the happenings of the day focusing on what you felt along with what happened.

2

I-AM-HERE-FOR-YOU NOTEBOOK

Buy a notebook where you would write down your feelings. This is your personal and private diary that is there for you when you need it.

4

YOUR WRITING PLACE

Find a place to journal. The place should be pleasant and calm so that you can recognize your inner voice.

6

NOTE-TO-SELF

Make a list of 3 qualities you would want to develop as an individual. Think about the time you were not able to effectively use these qualities and how you would want to improve in future.



7

ONCE UPON A TIME

Think and write about events in the past that made you happy. You can think about a family tradition such as being able to go out on holidays together or being able to spend quality time in home together.

9

I AM HAPPY WHEN

Write down 3 activities that brings you joy. Write about any recent experience you had with those activities and try to explore ways to include them in your life more frequently.

8

GRATITUDE NOTE

List 5 things you are grateful for in your life. These could be the people you know, the experiences of past and present, or even material items. Try to describe each of them elaborately. Experience and mention the emotions you feel while thinking about these things.

Journaling helps focus my thoughts and brings peace to my soul.



Caregiver Stories

..feel much more relaxed and calmer..

I had a very stressful day. My 15 year old son had a habit of touching and hugging people. Yesterday it happened again. He is a child with special needs. He doesn't know what he is doing but my neighbours judge me for not giving my child proper training. I brought my child to home and scolded him very badly. That night I felt very bad and I was writing the experience in my book. As I was writing, I realized that why did I even scold my child, it was my problem that I didn't tell those neighbours that he is special, scolding my child was my anger displacement towards their judgement. So next day I went to my neighbours and talked about my child condition, I felt so relaxed after talking to them. My neighbours were so sorry for earlier and told me that if I needed any they are there for me. I was so happy listening to them. Now "I feel much more relaxed and calmer".

..a must do for anyone facing a difficult situation in life..

This is the most beautiful and easy activity to do, yet the MOST powerful tool to declutter emotional baggage. The key here is to be consistent and write no matter how lazy or tired you are. I just keep writing about anything that comes to my mind at that very moment I don't have to think hard about what to write and how to start.

I just take the first step to write and everytime I write, I am surprised to know how much emotion baggage I have been carrying all my life. In the process of writing, I also discover new ways to deal with all the challenges in my life.

Journaling also helps me to connect well with my inner self. So, it's a must do for anyone who is facing a difficult situation in life.

MODULE 08

MUSIC

Heals Wounds that
Medicine Cannot Touch

Have you ever felt that caring for a person with special needs is the whole of your daily routine which is difficult to break?

Listening to music, or other pleasurable activities like art or hobbies like gardening can help break this monotony giving space for yourself and peace of mind.



Why is Music/Art Important?

- » Music relaxes the mind and helps in relieving stress.
- » Along with medication, music is now being used to treat pain, aid physical therapy and many other illnesses.
- » Music helps you stay positive, elevates your mood and provides motivation to keep going through physical pain.

Understanding Music

Psychological and physical health generally go hand-in-hand. At the time of distress, you must want even momentary relief to help you master the stressors effectively. It is at a time like this that music can do wonders. Music is a medium that will involuntarily help you share emotions and feelings with other people.

Have you ever wondered why elders sing every now and then? Studies have shown that making or listening to music or singing “lights up” areas of the brain associated with reward centers. These parts are also connected to language, those that process emotions. For instance, listening to lullabies not only calms down an infant but also helps them grasp the patterns of their native language, while simultaneously strengthening the bond between the mother and the child.

There is no other activity that can arouse emotions as deeply as music. The Indian classical music is built on concepts of *raga* (tune) and *bhava* (emotion). It can evoke specific emotions such as pleasure (*aananda*), sadness (*dukkha*), fear (*bhaya*), and anger (*kroda*) in anyone listening to it, beyond the barriers of languages. The movie songs you enjoy listening to follow the concepts of *raga*, *bhava*, and *tala* (rhythm). This is why some songs become popular.

All cultures have a variety of music to associate with the different aspects of life such as happiness, sadness, pain, heartbreak, struggle, or success.

How does Music help?

- » Singing has shown to improve metabolism, digestion, and blood circulation.
- » Listening to music calms the nervous system.
- » The vibrations in tunes can be relaxing and help reduce stress.
- » Listening to a slow melody when tensed or stressed helps slow down the heart rate and reduce the blood pressure, bringing an overall calming effect.
- » Music helps in re-connecting with self. It can take us to a familiar space within ourselves and helps us relax without any side-effects.
- » It helps ease pain and reduce anxiety.
- » It helps become mindful and stay in the present moment.

?

Did you know?

Music is the universal language of emotion.

?

Did you know?

Music can be our road to healing. It is one art form that is available anytime, anywhere and has an instant effect on everyone.

”

..improvement in speech..

Kala is a housewife and a mother who looks after her family and a 14-year-old child with developmental disability. She couldn't find any time in her daily routine to relax and focus on herself. Kala found music as her companion and with that, a new zeal to do her chores. She expressed that music makes her routine work more enjoyable. Even her child enjoys music. She has noticed he is now less disturbed and there is improvement in his speech.



5

Ways to add **MUSIC** in your daily life



1

WEEKLY MEDLEY

Every day, try playing different types of music.

- » 15 min - calming music
- » 15 min - uplifting music
- » 10 min - motivating music
- » 10 min - music to overcome sadness
- » 10 min - music to let go of anger

3

PLAY YOUR LIST

Make a playlist of the songs of your choice to listen to and relax at any time you need. You can even have different playlists for different moods or times of the day.

2

MUSICAL CHORES

Put on your favourite music while doing regular work such as cooking, cleaning, or stitching.

4

HAPPY BABY

Select and set a melodious tune as your morning alarm. You will find yourself waking up like a happy baby and with a lot of positive energy for the day ahead.



5

MUSIC EVERYWHERE

Listen to music while walking, driving a vehicle, and playing with your child. Adding music to these activities can make them fun and keep your worries at bay.



MODULE 09

THINKING DIFFERENTLY

**Calm Down, Think Differently,
and Find a New Way**

Caregiving brings forth challenges from time to time such as more time to understand the child's needs, different ways of training the child to learn the skills by using different methods and repeating the same thing etc. Finding your way through these challenges require 'thinking differently'.



Why is Thinking Differently Important?

- » There are always multiple ways in which you can respond to the challenges you face in life.
- » You cannot change or control an event, but you can change the way you react to it.
- » Positive experiences and constructively understanding and responding to challenges can reduce anxiety and depression and improve overall functioning.
- » The way you respond to different situations and challenges can affect your health.
- » Looking at the positive, negative as well as neutral aspects of a situation before drawing conclusions is called helpful thinking. Adopting such a thinking process can help in reducing stress.

Understanding Thinking Differently

How we think impacts how we feel. Thoughts have the capacity to trigger emotions. Any event, such as seeing a dog run towards you in a park, triggers emotions based on your perception of the event. If you are not familiar with dogs, as soon as you see it, you will feel afraid: *"the dog might attack me"*, or *"the dog might bite"*. But if you think of the dog as friendly and loving, you will reach out and pet it, also eliciting a positive response from the dog. The same situation can bring forth different responses and emotions in you based on how you think about, perceive, and understand it.

The way we think is based on our past experiences, what we have learnt, our opinions and beliefs about ourselves and the world around us. This also influences the way we look at and understand a situation or an experience. You may think that your feelings are the direct consequences of the event/situation you are in. But, it is really your thoughts that evoke the feelings. By developing a wider range of understanding and approaching situations, you can start experiencing more positive emotions and reduce the stress.

How does Thinking Differently help?

- » Thinking differently improves emotional and physical well-being.
- » It improves intellectual, emotional, and physical response.
- » It lowers anxiety and the risk of depression.

Tip



There are multiple ways to react in any situation. Thinking differently will help you feel in control.

Tip



You can learn to think differently by practicing changing unhelpful thoughts into helpful ones.

”

..dependent on her sister..

Kala is Mala's older sister who is a child with special needs. Kala has to forego her social activities to manage this responsibility. During a festival, Kala planned to visit her friend. But unfortunately, Mala had a seizure episode the day before and had to be hospitalized.

Kala felt bad about missing time with her friend and about how this could affect her friendship. She felt irritated and uncomfortable talking to her friend. Coincidentally, Kala got a call from her friend. When she learnt about Mala's condition, she was supportive.

She decided to come to Kala's house to spend time with her and help. "Mala if you need any help anytime, feel free to call on me." This crisis became an opportunity to strengthen her friendship.



Ways to

THINK DIFFERENTLY

1

ADMIT FIRST

Accept that you will face challenges and opportunities for growth in your journey of caregiving.

2

STOP-THINK-ACT

When a challenging situation presents itself, instead of reacting immediately, **stop** to reflect on it, **think** of the different ways in which you can respond to it, and **act** in the best possible manner.

3

READ TO LEARN

Read about caring for a child with special needs and learn the different ways to understand and modify their behaviour.

4

IT'S NOT ABOUT YOU

If you personalise the challenge, you may not be able to manage it. Avoid thinking that you are not capable or good enough, or that only the worst things happen to you.

5

ONLY THIS BIG

Any problem is only as big as you make it to be. Avoid thinking of the problem you face as unsolvable.

6

NETWORK WORKS

Reach out to your support system and the people around you to seek their suggestions on the challenge you are facing. They might give a new outlook on the situation; share how they would address it based on their own life experiences.



7

DON'T HESITATE, ASK FOR HELP

Getting help from those around you can decrease your burden and make you feel stronger. It will also give you alternatives to look at and respond to a situation.

8

KEEP CALM

As you solve the problem, try to find relief in pleasurable activities such as listening to music, drawing/painting, gardening, or praying. (See [Module on music](#))

9

LEARN FROM LIFE

Make an effort to learn something from every situation. This will give you the ability to look at a situation from many different angles. Greater the choice, the lesser distress you will feel.

Happiness is a choice that we make every single moment. Life is a series of experiences, and it's our perception of them, that makes them good or bad, or joyful or ridden with sorrow and stress. This means in choosing to look at things differently, we can also change the emotions that we experience.

Gopika Kapoor, Beyond the Blue

Caregiver Stories

..empathize with other parents..

By being a caregiver of my child, I have learnt many things in my life. Because I have her I was able to learn to be more patient and I am able to empathize with other parents who have special needs and marvelling at this deep space of calm acceptance. When work gets hindered, my agitation seems mild. Last week we lost a dear person in our extended family. That was a very important time of learning for me and I was able to recognize while I was writing it.

..lifelong as a companion..

My elder daughter got married and left for her in-law's house. I was worried about how I will live with my husband alone. But then I thought, 'I will have Madhu (My child who has special needs) lifelong as a companion and I can teach her all the skills she needs to live independently and give her a new life, as she has given me a purpose to live in the initial days of my struggle. She is definitely a god's gift.

**I learned from my life
that we can find things to
celebrate even when we
are in a shipwreck and in
the middle of the ocean,
on a lifeboat.**

Ayesha Chaudry - GIFTED (2021)



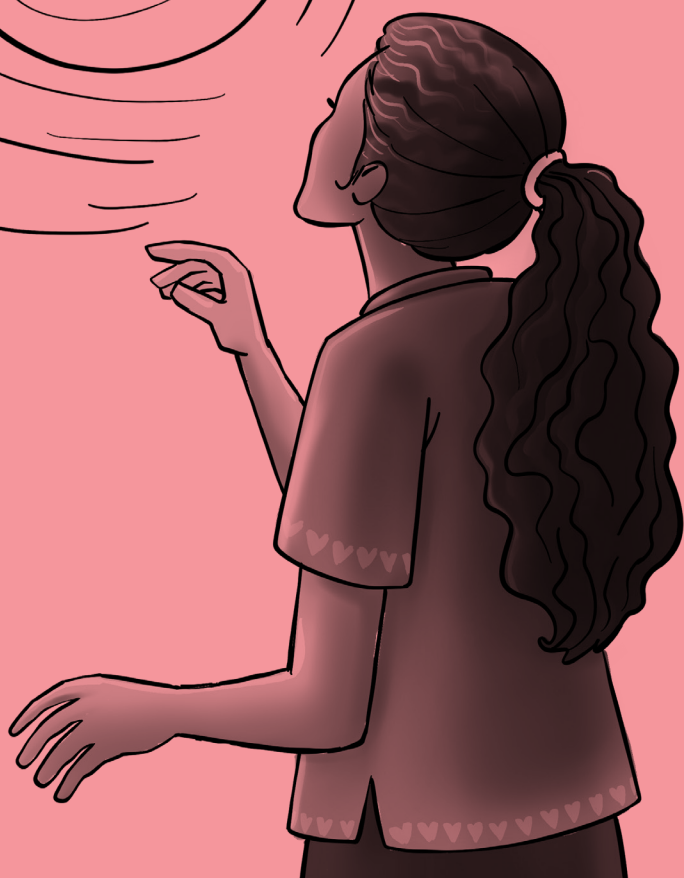
MODULE 10

SPIRITUALITY

A Path to Becoming Your Best Self

Caregiving is a source of fulfillment and evokes feelings of empathy, love, and care. Spirituality provides an opportunity to use these feelings toward personal growth and is available to all caregivers.

“My faith has become stronger”



Why is Spirituality Important?

- » Spirituality is a force of positivity and is for everybody.
- » It is associated with longer life and better health.
- » It offers the pathway to personal growth and helps you become a better person. It leads to a sense of fulfilment.
- » It helps in accepting situations and finding meaning in adversity.
- » Every community and religion offer spiritual ways to understand and make sense of the experiences of life.

I have become more active towards helping other parents with special children.

Understanding Spirituality

All of us are parts of our communities. Each community has its own way of connecting to the larger power, often called 'God'. Religion is simply an aspect of spirituality systematized for individual practice and community living. This means that you can be spiritual without necessarily being religious.

Each person/family practices their religion or spirituality in their own way. Some carry it within

themselves as a belief, others practice it through rituals. Yet others look for an intellectual way of understanding spirituality and life through gratitude, surrender, kindness, compassion, suffering, disabilities, sorrow, and other emotions.

Spirituality is best understood when you find your own way of pursuing it. There is no single or right way to practice religion and spirituality.

How does Spirituality help?

- » Studies have shown that people who practice spirituality live longer and healthier lives.
- » Spiritual people are less likely to experience depression, suicidal thoughts, and drug addiction.
- » Spiritual people are likely to have a stronger support in the community.
- » Spiritual People are more regular and better able to manage long-term treatment such as HIV or cancer, and get better benefits from the treatment.
- » They recover better from illnesses such as diabetes, heart attack, stroke, and cancer. During the COVID-19 pandemic, people who were spiritual and practiced methods like mindfulness had fewer adverse effects.



Tip

Spirituality is a resource for everyone. Dip into it to become stronger and find mental peace and happiness.

The surgeons could never fix my leg but thankfully, they managed to give it a shape that allowed me to walk. But God made sure that it was good for running. He also gave me a fighting spirit.

Girisha H N - GIFTED (2021)



..prayed to God..

I get very much angry at God, thinking, "What did I do, why me?" I have prayed to God that I will give a silver crown to Him if my daughter will recover and be able to stay home and behave appropriately." But nothing had happened. My husband believes a lot in God and says He will help us. So now I have started to leave all the burden of my pain and misery on God and expect Him to guide me through it.

Mrs. Anjali,
Mother of a child with special needs.



Ways to make

SPIRITUALITY

a part of your life

1

SEEK GUIDANCE

Talk to and seek the guidance of spiritual leaders in your community.

3

READ AND MOTIVATE

Read religious texts regularly to understand your relationship with the higher power and the meaning of life.

5

PRACTICE

Practice rituals like offering worship, fasting, and participate in celebrations that are part of your family/community.

Join in prayers, worship, and spiritual talks.

2

CHOOSE WHAT'S RIGHT FOR YOU

Choose the religious/spiritual path that you find meaningful and feel comfortable with.

4

SURRENDER

Work toward surrendering your life to the higher power.

6

LISTEN, OBSERVE AND LEARN

Make an attempt to learn from the experiences of other people as much as possible. It will help you become a better version of yourself.



7

VISIT

a temple, church, mosque, gurudwara, synagogue or other places of worship.

8

EXPRESS

gratitude daily.

9

PRACTICE COMPASSION

and kindness toward others as much as possible.

“

our blessing from God..

God has chosen us as his parents because He knew that we would be strong enough to be able to carry him in our arms for as long as we are alive. He is our blessing from God. He is God's child!"

Mrs. Pranithi,
Mother of a child with special needs.

10

MAKE PRAYING

and meditating a daily practice and part of your life.

Caregiver Stories

..He gave us strength..

Sometimes nothing works. All we can do is wait for him to calm down and keep trying all the things that we can. I believe Allah is there for us. We live because we believe in Allah. Actually, He gave us a special child but at the same time, He gave us the strength to look after this child. He gave us patience, and He knows that we can bear this child that's why He gave him to us.

Mrs. Mumtaz
Mother of a child with special needs.

Spirituality is a journey and not a destination.

We should not take too many things for granted and we should devote more time to faith in God. This is what gives you the strength to go on and continue on your chosen path even though it is so difficult to put the past behind you.

Suresh Advani - GIFTED (2021)

..God showered his blessings..

The things that happen in my life are not in my control and I am not sure what happens with the child either. I feel that God showered me His blessings through this child who has special needs looking at my difficulties all my life. It is God-given and it is our responsibility to take care of our child.

Mrs. Rabia
Mother of a child with special needs.

Module 11: Seek professional help

The above measures will help you to master most of the changes and challenges of caregiving and find purpose of life.

You/your family will need to specialist help in the following situations:

- » You want more guidance to incorporate the above psychological measures to your emotional health;
- » Your emotional distress is associated with many life challenges that you cannot handle;
- » Your emotional distress is interfering with daily routines (self care, eating, sleeping, work) or your treatment;
- » You have continuous feelings of tension, worry, irritability sadness, crying, anger, suicidal thoughts, that is causing distress to you;

Remember taking professional help for emotional distress is similar to taking help for physical complaints.

In conclusion, caregiving can be demanding on the caregiver. Caregiving is also fulfilling for the caregiver. Caregivers emotional health is important not only for the caregiver but also for the care receiver. Your goal should be to minimize the stress of caregiving and maximize the positive feelings of caregiving.

Appendix 1: Resources and further reading

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Appendix 1: Resources and further reading

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26. Schmitz K H (2019) Exercise is Medicine in Oncology: Engaging clinicians to help patients move through cancer, CA Cancer J Clin. 69(6): 468-484. doi:10.3322/caac.21579.

Icons and illustrations

1. The icons on the cover page are attributed as following
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5. Other icons have been sourced from [healthicons.org](#), a free and open source platform for commercial and personal projects.
6. Nutritional Pyramid from [freepik.com](#)

Appendix 2: Self Reporting Questionnaire (SRQ, WHO 1980)

Name

Date:

	Yes	No
Do you often have headaches?	<input type="checkbox"/>	<input type="checkbox"/>
Is your appetite poor?	<input type="checkbox"/>	<input type="checkbox"/>
Do you sleep badly?	<input type="checkbox"/>	<input type="checkbox"/>
Are you easily frightened?	<input type="checkbox"/>	<input type="checkbox"/>
Do your hands shake?	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel nervous, tense or worried?	<input type="checkbox"/>	<input type="checkbox"/>
Is your digestion poor?	<input type="checkbox"/>	<input type="checkbox"/>
Do you have trouble thinking clearly?	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel unhappy?	<input type="checkbox"/>	<input type="checkbox"/>
Do you cry more than usual?	<input type="checkbox"/>	<input type="checkbox"/>
Do you find it difficult to enjoy your daily activities?	<input type="checkbox"/>	<input type="checkbox"/>
Do you find it difficult to make decision?	<input type="checkbox"/>	<input type="checkbox"/>
Is your daily work suffering?	<input type="checkbox"/>	<input type="checkbox"/>
Are you unable to play a useful part in life?	<input type="checkbox"/>	<input type="checkbox"/>
Have you lost interest in things?	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel that you are a worthless person?	<input type="checkbox"/>	<input type="checkbox"/>
Has the thought of ending your life been on your mind?	<input type="checkbox"/>	<input type="checkbox"/>
Do you feel tired all the time?	<input type="checkbox"/>	<input type="checkbox"/>
Do you have uncomfortable feeling in your stomach?	<input type="checkbox"/>	<input type="checkbox"/>
Are you easily tired?	<input type="checkbox"/>	<input type="checkbox"/>

Total yes Score:

Emotional Health Care Checklist

List of Activities	Current Practice	Goals	Steps for Action
ACTIVITY 1 EXERCISE/WALKING (20-30 minutes every day)	Yes/No		
ACTIVITY 2 SLEEP (6-8 hours, everyday)	Yes/No		
ACTIVITY 3 NUTRITION (eat fruits and vegetables daily.)	Yes/No		
ACTIVITY 4 YOGA/MEDITATION (15 – 30 minutes daily.)	Yes/No		
ACTIVITY 5 CONNECTEDNESS (Regular contact with people/organization that can support you and remember to reach out to them in times of need)	Yes/No		
ACTIVITY 6 WRITING FEELINGS AND THOUGHTS (20 minutes daily before sleeping- write down your thoughts and feelings in a dairy.)	Yes/No		

ACTIVITY 7 MUSIC /ART (Listen to music every day.)	Yes/No		
ACTIVITY 8 SHARE YOUR FEELINGS (Share happiness and distress regularly with people who matter to you)	Yes/No		
ACTIVITY 9 SPIRITUAL PRACTICE (Connecting to higher power of your choice)	Yes/No		
ACTIVITY 10 THINKING DIFFERENTLY- HOPE (Looking at positives in all situations)	Yes/No		

Instructions for the SRQ

1. These are the questions regarding the symptoms of your health.
2. you will have to answer with "YES" OR " NO" if you have had these symptoms in the past 1 month.
3. There is no right or wrong response.

Instructions for Health Questionnaire

1. These are the 10 health activities that could be done to better health.
2. Mark "yes" if you have a habit of practicing these activities.
3. Mark "No" if you have not been able to practice it or never tried the activity.
4. There is no right or wrong answer.

Appendix 3: Professional responses to the Intervention package on 'SELF-EMPOWERING for EMOTIONAL HEALTH'

By The Association for the Mentally Challenged (AMC), Bangalore.

Ms. Annie Alexander, Bangalore

This work stands with high quality. Congratulations. The module is comprehensive in itself, so I have few comments.

Dr. Meenu Anand, Delhi School of Social Work, Delhi.

Broadly speaking, the modules are elaborate and interesting with pictures and illustrations. I do think that if we add 'Learning outcomes' at the beginning of each module along with 'Summary/ Take Aways' at the end of each module, it can be strengthened.

Prof. Priti Arun, GCMH, Chandigarh.

This will definitely prove to be invaluable to all those working in the field of disability.

Prof. Ajit Awasthi, (Retd) PGI, Chandigarh

I have gone through all the modules. These are highly practical, easy to understand and apply in real life. The format as well as the pictorial illustrations make these interesting and attractive. All in all a commendable effort towards public health messaging and implications.

Mr. Amrit Bakhshy, SAA, Pune

I have watched the video and have gone through the contents of all the ten chapters of the draft of the book. Needless to say, a lot of hard work has gone into this project. Illustrations are apt and help in understanding the point being made. From a caregiver's perspective, I have given a few comments in the first few chapters. Usefulness of peer support groups need emphasis.

Prof. Srikala Bharath, (Retd) NIMHANS, Bangalore

A proactive step to empowering carers of parents with children with special needs. Self-Care being the focus of the modules is excellent.

Dr.Vandana Gopikumar, Banyan, Chennai

I already find them robust, simple and engaging.

Ms. Suman Gupta, Social Work, Chandigarh

It was a pleasure to go through the well prepared Draft. Wish you all the best for the good and valuable work you are doing for the society. God bless you.

Dr.Aarti Jagannath, NIMHANS, Bangalore

It was enriching for me to go thru all the material sent across by you.

Ms.Anuradha Kapani, Social Work. Bangalore.

Very extensively thought out, I must say .The chapters on journaling and spirituality were particularly Interesting . Would certainly benefit from all the well thought out suggestions regarding health, well-being and the forces which would enable them to cope better with the challenge in their lives.

Prof.Malavika Kapur, (Retd)NIMHANS, Bangalore

It is very good and I am only making minor suggestions.

Dr. Kishore Kumar, Banyan, Chennai

Over all it has come out very well, some needs little more additions.

Dr. Siva Kumar, NIMHANS, Bangalore.

Offered support through extensive editing of the material.

Dr. Pallab Maulik, George Institute, New Delhi.

The topics are all good but I feel there are too many words and lot of science in them for the lay public. Depending on whom you are targeting these documents will need to be curated, significantly.

Ms. Susheela Mohandas, Bangalore

I had gone through all ten attachments. A lot of work gone through by you in preparing it.

Dr. Nagarajiah, (Retd) Nursing, NIMHANS, Bangalore

The guide has come out very well, I have no words to comment on it. I have added few things.

Dr. Jayanthi Narayan, Special education., Hyderabad

It is a good move that the State Resource centre of National Trust is involved. This will help the material reach far and wide. With the custom-made pictures and page making, I am sure these modules are going to attract more users.

Ms. Sunita Patra

'No matter how things are in my external environment, I always try to find some time to reconnect with my inner self.'

Dr. Shashi Rai, Psychiatrist, Lucknow

They are all very well written, except the one on nutrition had some mistakes.

Mr. Prasad Ramalingam, Bangalore.

I have just gone through the modules, must say your team have put in a lot of thought and effort in shaping it.

Dr. Usha Ramanathan, Legal expert, Bhuvaneshwar

I would suggest that the statements are made positively rather than stress on the negative. For instance, saying 'prone to develop lower self-esteem, feel depressed and experience mental health issues' may be replaced by stating the positive, of what they look for- happening.

The episode with which you begin, with Arun Shourie, is incomplete. It leaves us with the feeling there was something prophetic about his friend's prediction of what his life would become. I am not sure that is how Arun Shourie treated it, and I wonder if he would want it depicted thus. May be you would want to reconsider it.

Ms. Chitra Shah, ASHA, Puducherry

I have gone through the guide. It is fine. I think it is easy and simple for people to understand. Mental health I guess is the most important need of the hour.

Dr. Prateeksha Sharma, Mental Health Therapist, Goa, Gurugram

I looked at the module you shared with me in a cursory way by skimming through it quickly. It seems to be complete already.

Dr. Sangeetha Shyam, New Delhi

I am really glad to see such a project happening for catering to the needs of caregivers.

Dr. V. Sridhar, BR Hills, Karnataka

Overall it is very good and it addresses all the needs of a care provider. It is amazing that you have thought of all the possible approaches.

Dr. Nirmala Srinivasan, Bangalore

It's an interesting and stimulating exercise no doubt. Sincere thanks for giving me this opportunity.

Dr. Sivakumar T, Rehabilitation, NIMHANS, Bangalore

Provided extensive editorial suggestions. The suggestions were very valuable for finalisation.

Ms. Romola Thomas, Social work, Bangalore

Provided extensive editorial suggestions. Very valuable.

Dr. Pamela Trotman, Social Work, Australia.

Good morning Murthy, I've been musing on the first quote in the guide... about how a special child will change your life forever. When I read this I heard generations of parents saying just how much becoming a parent had changed their lives, to the extent that they were forever changed.

I thus think you may only need to provide a different introduction which normalises the challenges of being a parent, whilst acknowledging the additional challenges presented by having a 'special child'.

Mr. Anil Vartak, EKALVYA, Pune

Great achievement and congratulations!

Dr. Meena Vythilingam, Psychiatrist, Washington, USA.

Absolutely happy to support an important and meaningful project.



About AMC

AMC was started in 1960 by Dr. D. L.N. Murthy Rao, then Director of All India Institute of Mental Health, Bangalore (now NIMHANS). AMC is a one-of-a-kind institution providing lifelong support for 120 – 140 individuals with Developmental Disability Disorders (DD). AMC is working with the goal to improve the quality of life of persons with developmental disabilities and their families. The wide range of services offered at AMC are provided free of charge, as 90% of the beneficiaries are from low socio-economic background.

Mission

To promote development, independence, economic sufficiency, community inclusion, self-determination of persons with IDD; Empowerment of their families through coordinated services of training, research, technical assistance and dissemination activities. AMC has the following facilities: special school, multi-category vocational training center, sheltered workshop, day care center and Samruddhi, a programme to support families. The other free services provided are: supply of uniforms, shoes, bags; milk with multi millet porridge, vitamin supplements; nutritious lunch everyday; transport facility for everyday commute; outdoor activities like visit to exhibitions, fairs, picnic, etc. and yoga and training in painting, dance and music.



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