



PSYCHOSOCIAL MATTERS

THE APSWP NEWSLETTER

• Newsletter – No. 5

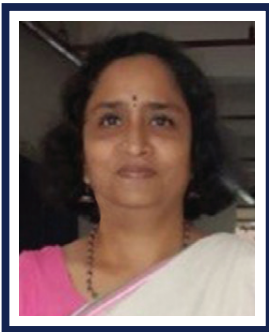
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• July 2022

IN THIS ISSUE :

- An activist shares her journey from classroom to field
- A personal caregiver shares the meaning of unbounded love
- A therapist argues for women to care better for themselves
- The Exploding Head Syndrome is briefly defined
- An anonymous poem tells us to speak, or the body will!

MESSAGE FROM OUR PRESIDENT

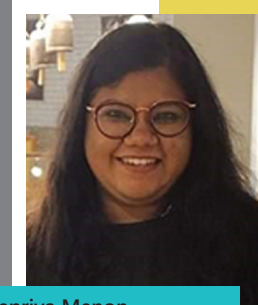


Greetings everyone! Hope all are in good health and good spirits. At the outset I want to offer condolences to Professor P Illango's family, friends and colleagues on his demise on 10th March 2022. A life member of APSWP, Dr. Illango was well known for his work in Gerontological Social Work in India. With his passing on, Psychiatric Social Work has lost one of the most experienced and active members of the fraternity.

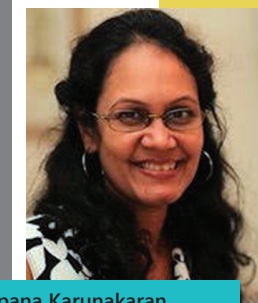
On a happier note, recently, APSWP added another feather to its cap. It successfully conducted its first election to its Governing Body for the new term consequent to the ending of the tenure of the founding Governing Body. I would like to thank all the members for their active participation and faith in the elected members. I welcome all the newly elected members of the Governing Body and remind each one of us that we have a long road full of tasks ahead of us!

The current condition of the world filled with wars, riots, unemployment and innumerable other traumatic events calls for us mental health professionals to rally around and extend our professional hand to people in need. Our association has shown its commitment towards contributing to the wellness of our society during the pandemic time. Our profession needs recognition and acceptance from the decision-making bodies. This requires a collective effort, resilience and positive outlook. This edition of the Newsletter reminds us of the importance of some of these attributes through well written and composed articles. Once again our Editor and her team have brought out a meaningful and inspiring newsletter!! A big round of applause to them!! Wishing all of you a peaceful life ahead.

Sobhana H



Sreepriya Menon



Kalpana Karunakaran



Rameela Shekhar

CONTRIBUTORS TO THIS ISSUE



Friends, this is the fifth newsletter of our young APSWP. The members of our Edit Team take turns at writing the editorial and in this issue, my message is 'Navigating to Well-being'. Life certainly isn't easy these days, and navigating to well-being needs to be the mantra to be the best we can be, especially as **psychosocial care providers** for the needy. It would be effectively reflected in our persona and felt by our service users if we lived by the rule ourselves.

There is beauty everywhere and ugliness too. Why do we focus on the ugly and carry it in our heads, breathing in disgruntlement, frustration, regret, hopelessness? Can we make a conscious choice to appreciate and internalize the joyful moments, linger on them, breathe them in, re-energizing every cell in our body and creating chains of positivity sparks? Can we focus on making

ourselves a wee bit better by counting blessings and filling ourselves with beauty, possibilities, love and gratitude? Look around. You see a magnificent tree. You also see carelessly thrown filth that stray dogs are tugging at. You choose to ignore the beautiful tree and focus on the ugliness of the filth strewn about. Yes? You see two large buildings adjacent to each other with their numerous balconies drying clothes. The cool breeze generated by the 'tunnel effect' of the buildings is ignored as we comment on the ugliness of the buildings and the sordidness of their occupants!

Much as we talk about **Life Skills** and engage in training people in them, many of us do not practice them in our own lives. There is zero **critical or creative thinking** involved in solving our routine problems or **appreciating the diversity** surrounding us. Most of us reading this piece are educated, economically independent, and not constrained from thinking freely. We can exercise our individuality by pushing aside meaningless societal expectations and determine what we want for ourselves in order to be the best versions of ourselves each day. Yet, we often don't.

Decades of work with late adolescent and young adult students provided me with the rich and yet unsavoury privilege of observing how much others' expectations and lack of critical thinking affected the students' lives. Most did not identify their genuine needs and assertively express their own thoughts and desires, and this resulted in their ongoing unhappiness. When they landed in trouble and chose to seek help, it showed clearly how their low self-esteem-helplessness-angst-negative energy permeated into the atmosphere resulting in unhealthy interpersonal relationships, undesirable habits, and poor academic performance, to name a few of the consequences. Exposure to life skills wasn't evident in their behaviour, 99% hadn't heard of it.

Primary prevention of mental health problems is the most cost-effective plan of action that we PSWs can help to spread. Primary prevention starts with Positive and Critical Thinking! Nurture the eye to see that the glass is always half-full, never half-empty!! Celebrate the half-fullness and accept the half-emptiness. And let us start with ourselves. No leader is as good as the one who leads by example.

Shalini K. Sharma



FROM JANUARY TO JUNE 2022...OUR SECRETARY SPEAKS

Hello! While Covid continued to exert influence on life everywhere, it was nevertheless a fairly busy half-year for APSWP.



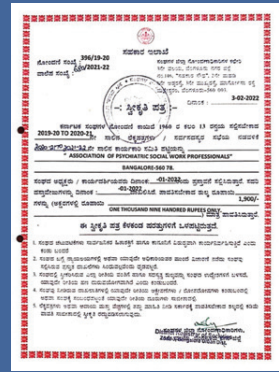
1. Elections to the Governing Body

Let me begin by recounting that the tenure of the Founding Governing Body ended early this year and elections had to be conducted to position the new Governing Body. It was our first experience of conducting an election and the challenge was compounded because of the pandemic, the lack of in-person meetings, and therefore, the need to carry out the whole procedure online. It is with great satisfaction that I report that we were able to successfully complete the exercise complying with all the procedures and maintaining all the needed safeguards. APSWP member Vidya Ramachandran was appointed as the Returning Officer. Call for nominations was made in January 2022. The Nomination Form was circulated to all members of the General Body on 28th January 2022 with the request to send in their nominations by March 5, 2022. Thereafter, the nominated persons were contacted and their willingness/non willingness about their nominations were received till 10th March 2022. It is to be noted as an indicator of their performance that the President, Vice President, Secretary, Joint Secretary and Treasurer were elected unopposed and the elections had to be conducted only for the 6 positions of Members. The online election was held on 22.03.22 and results were announced on 23rd March.

I take pleasure to include in my report the list of new Office Bearers of APSWP for the period upto March 2024 :

Sl. No.	Post	Name	Status
1.	President	Dr. Sobhana H	Elected unopposed. Second term as President. Currently with LGBRIMH, Tezpur
2.	Vice-President	Dr. Manisha Kiran	Elected unopposed. Second term on Governing Body but first term as Vice-President. Currently with RINPAS, Ranchi.
3.	General Secretary	Dr. Aravind Raj	Elected unopposed. Second term as General Secretary. Currently with NIMHANS, Bengaluru.
4.	Joint Secretary	Dr. Renjith R. Pillai	Elected unopposed. Second term as Joint Secretary. Currently with PGIMER, Chandigarh.
5.	Treasurer	Dr. Jobin Tom	Elected unopposed. Second term as Treasurer. Currently with IMHANS, Calicut.
6.	Member	Dr. Kavita Jangam	Newly elected. Currently affiliated to NIMHANS, Bengaluru.
7.	Member	Dr. Ragesh	Elected as member for a second term. Currently with IMHANS, Calicut.
8.	Member	Dr. Sayee Kumar	Newly elected. In private practice in Chennai.
9.	Member	Dr. Satapdi Chakraborty	Newly elected. Currently with Dr. RML Hospital, New Delhi.
10.	Member	Dr. Upasana Baruah	Newly elected. Currently with IHBAS, New Delhi.
11.	Member	Dr. Mary Tariang	Newly elected. Currently with Christ (deemed to be) University, Bengaluru.

I wish the Governing Body good luck and a productive tenure.



2. Renewal of registration of APSWP

As you know, the registration of any Society has to be renewed every year and Covid had brought some interruption in this process. I now report with happiness and relief that the renewal was completed for the financial years 2020-21 and 2021-22. The renewal for the current financial year is under process.

3. Continuous PSW Education (CPSWE) Programme

We were able to arrange two programmes in this half year, as follows :

Sl. No.	Dates	Topics	Resource Persons
1.	January 31, 2022	Mental Health and Insurance	Dr. T. Sivakumar Addl. Professor, Dept. of Psychiatry, NIMHANS, Bengaluru
2.	May 28, 2022	Recovery-oriented practice in a mental health setting	Dr. Josy K. Thomas Working in the areas of child wellbeing and family safety in Melbourne, Australia.

4. Association Meetings

Four meetings were held in this half-year, as follows :

Sl. No.	Dates	Meetings	Place
1.	January 10, 2022	5 th meeting of the Core Group	Online
2.	January 10, 2022	11 th meeting of the Executive Committee	Online
3.	March 29, 2022	3 rd Annual General Meeting	Online
4.	March 29, 2022	12 th meeting of the Executive Committee (newly elected)	Online

5. Communication with Various agencies

As in the past, PSWs continue to face discrimination in various ways and from various quarters, and letters have been written to tackle this issue :

- 31.01.22 – Letter (Ref No.01/2022) to Maharashtra SMHA regarding the qualification for the non-ex-officio member PSW. I am happy to report that this letter has been forwarded by the Principal Secretary to the Joint Secretary for needful action.
- 27.04.22 – 2nd Letter (Ref No.02/2022) to the Director, MIMH, Pune, regarding the qualification for the Faculty post of PSW
- 28.04.22 – Email to the Under Secretary, Ministry of Health and Family Welfare, Government of India, regarding objections and alternate suggestions regarding qualifications in the draft Recruitment Rules for the post of Junior Psychiatric Social Welfare Officer at CIP, Ranchi.
- 04.05.22 – Letter (Ref No.003/2022) to Director, AIIMS, Kalyani, West Bengal, regarding the qualification for the post of PSW.
- 07.05.22 – Letter (Ref No.004/2022) to the Member Secretary, RCI, New Delhi regarding inclusion of PSW in RCI.
- 07.05.22 – Letter (Ref No.005/2022) to Maharashtra State NEP Executive Committee Member regarding continuation of M.Phil. PSW programme.
- 28.05.22 – Letter (Ref No.006/2022) to the Joint Secretary, Dept. of Health and Family Welfare, Govt. of Kerala, regarding inclusion of PSW as a member in the expert committee to evaluate the status of mental health centres in Kerala.

6. Membership details

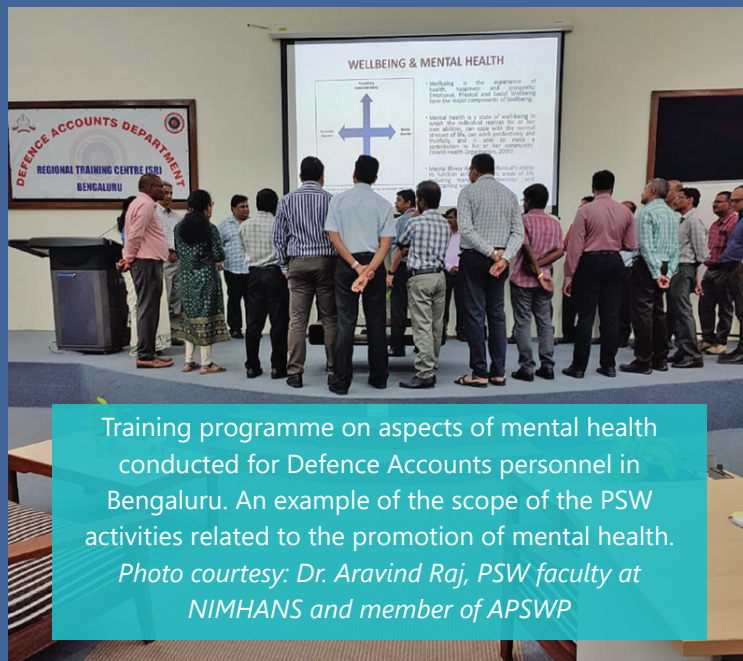
APSWP now has 205 Life Members on record, up from 195 in December 2021. Unfortunately, with the passing of Dr. Illango, the actual life membership number is 204. We also have a single Student Member as of now. Identity Cards for members is under print and will hopefully be available for distribution soon.

7. Website

The APSWP Website continues to show some problems but has now been revived and will hopefully be fully functional soon.

I end with the hope that APSWP will go from strength to strength in meeting the aspirations of its members, the PSW fraternity, and our client communities.

Aravind Raj



Training programme on aspects of mental health conducted for Defence Accounts personnel in Bengaluru. An example of the scope of the PSW activities related to the promotion of mental health. Photo courtesy: Dr. Aravind Raj, PSW faculty at NIMHANS and member of APSWP

Lead Essay

By Rameela Shekhar



It's Time To Prioritize The Emotional Health of Women...

Rameela Shekhar studied Psychiatric Social Work at NIMHANS and went on to teach at Roshni Nilaya, Mangaluru where she spent 34 years in senior capacities as Professor, Head of the Department, and Dean of Post Graduate Studies. She then went on to found Manashanthi Counselling, Training, and Research Centre where she continues to remain active. Her focus has been on family life, family relationships, mental health of children, stress management, mental health first aid, and related areas. She has extensive experience as a trainer for a wide range of participants in India and abroad. She is also an active researcher and public speaker on mental health.

A simplified definition of Mental Health goes as *a successful performance of mental functions resulting in productive activities, fulfilling relationships with other people, and the ability to change and cope with adversity.* In other words, it includes our emotional, psychological and social wellbeing. Mental disorders can affect men and women differently and, therefore, the methods in dealing with them too differ. For the purposes of this article, I have drawn exclusively from my personal experiences as a mental health practitioner and a teacher as well as a woman navigating my own healthy psychosocial path in life.

It is a general observation that while conditions like Schizophrenia and Bipolar Disorder show no difference in the rates at which men and women experience these illnesses, there are other problems like Anxiety and Depression that affect more women than men. Besides them, there are certain mental health problems that are experienced uniquely by women, like Perinatal Depression, Premenstrual Dysphoric Disorder, Perimenopause-related Depression, and so on.

The question of importance is not what mental illnesses women succumb to; rather, it is in understanding why women are more vulnerable to these disorders. The answer lies in the various factors that affect women's mental health. A few examples are given that are quite typical and widespread even in modern societies.

- If an observation has to be made on who the main caretaker of a family is, especially of the children and older or disabled relatives, we notice that in spite of all the strides made by society to become more inclusive and egalitarian, it is still most often the women of that family. This restricts them from going out and having a social life apart from family, leading them towards social isolation which is linked to several mental health problems.
- Women are seen constantly concerned about their personal safety when they are outside and even when they are alone at home. Women are comparatively much more exposed to physical, emotional and sexual abuse than men. Because

of this, their movements are restricted by others (parents, elders) as well as by themselves ("I should be home before it gets dark"). This can become quite frustrating, especially in the case of women who are strong, educated, and have independent minds.

- Often a woman's stress is not even recognised, for example when a working woman has had a long day at work, a long commute home, and then immediately has to get to work on cooking dinner, helping with the children's homework, looking after the elderly, and taking care of guests who drop in – day after day after day. Even when she expresses her emotions, they are trivialised by others ("As if it is so difficult to make a few cups of tea for friends"). This often becomes both physically and mentally exhausting.



- Unfairly treated or abused women very often choose to keep quiet rather than verbalize due to stigma and taboos. This can be due to embarrassment, fear of judgement, or other reasons that drive them towards social isolation and make it hard for them to talk about difficult feelings, thus, making them simply choose to internalize them. Especially in the case of sexual abuse – but also in the case of other stresses and strains – speaking can result in further victimisation of the victim herself.

- Since birth, girls are encouraged to think about others more than themselves. Their significance is hinged on their being 'good' daughters, wives, daughters-in-law, and mothers. They are evaluated on the time they give to others, whether or not they are appreciated for it. One of the adverse consequences of such upbringing is that women feel a great sense of guilt when they do things they personally enjoy, if it does not somehow involve their families as well.
- To add to the above, there are hormonal and other biological influences on women related to puberty, pregnancy, childbirth, menopause, etc. that have a significant bearing on mental health.

The effects of all these forms of repression, control, marginalisation, and biological factors are seen through many psychological disorders, e.g. Post Traumatic Stress Disorder (PTSD). When a woman undergoes physical or sexual abuse, there is long term impact on her mental health, especially if she has not received any support coming her way. And as already mentioned a woman's tendency of keeping quiet and facing all problems alone without sharing them with anyone keeps her at a greater risk of having poor mental health.

To get a wider perspective on this, let us go through an illustration of the life of a young woman of around 38 years brought to clinical set up with features of tiredness, fatigue, headache, lack of sleep, poor appetite, and lack of initiative to do any household chores. Initially she was reluctant to open up about the situation at her home. She simply kept asserting that everything was fine, it was just these physical problems that were hindering her from doing her household chores. **Psycho education** helped her to understand the relation between mind and body and it was then that she opened up about her status at home which was just that of a caregiver and household worker. She had a post graduate degree and a great desire to work on a job outside the home. Unfortunately she was not encouraged to do so and on the domestic front all that she received for everything she did was just critical comments and lack of importance. **Individual sessions** on building self esteem, assertiveness training and **family therapy** helped her verbalise her desires and stand for her rights.

In yet another instance, a woman aged 55 came with complaints of feeling sad, dejected, and miserable for no apparent reason. She tried to reason it out by saying she had neglected her children when they were young as she had been employed outside the home at that time. In addition, she also continues to complain of somatic



pains for which physical causes have been ruled out by physicians. Loss of sleep and appetite are also in her list of concerns regarding her health. She is now under therapy for depression related to peri-menopause, which is quite common in middle aged women. Thus, in mental health interventions, **apart from psychosocial factors one must also keep in mind biological factors that may be causing problems.**

In the context of Covid, women have been affected mentally more than men, be it frontline workers or homemakers. Psychological and psychiatric risks faced by women both as patients and as workers in the health care sector have increased. Not just that, the level of risk of violence against women at home and at work has also increased. Cases of domestic violence against women have multiplied in number significantly after the viral outbreak. Therefore, home for many women, has not been a safe space during the course of this pandemic. The lack of adequate emotional and domestic support have added to the poor mental health status of women facing these issues. Risk of anxiety, depression and PTSD have been much higher during the pandemic times. Intimate Partner Violence (IPV) is another issue that puts women under the threat of mental health disorders. IPV includes physical and sexual violence, emotional abuse, and stalking. One of the risk factors commonly associated with intra-family violence is male aggression with or without alcohol, which often appears as a mode of reaction to a crisis.

Now that we have discussed a few basic commonly experienced mental health issues in women, we need to educate ourselves and the women in our contact circles on how to improve one's mental health. Here are some tips that we use in our clinical practice:

- Women need to plan their 'ME TIME', which is time that they spend on themselves, with themselves, and on activities of their choice. It is very important for women to appreciate themselves. They must know what they like to do, and they must give time to do those activities and, most importantly, **do it without feeling guilty.**

- Women need to build supportive relationships. They must know to ask for help when they need it. Women have to be helped to understand that they need not suffer alone. In fact, they must not suffer at all, if help is available.
- It is also about time that we all talk about mental health in a way that normalises it so that seeking mental health therapy is appreciated rather than treated as a matter to be kept hidden.

As Mental Health Professionals some of the approaches that can help women in distress :

- Listen attentively and acknowledge all the expressed feelings.
- Provide reassurance, make them feel understood.
- Educate them about mental health to promote their social and emotional wellbeing. Explain the body-mind connect.
- Motivate them to develop skills for productive engagement, whether for income or as a hobby.
- Use appropriate therapeutic interventions

- Work in a team so that the woman benefits from a holistic intervention approach.

When women speak about their problems and verbalize their mental conditions, fifty percent of the work towards better emotional health is done. Women must remember that they are strong pillars of this society. When they become aware of themselves with all their strengths and weaknesses, they gain the confidence to face their particular situations. When women work towards the betterment of their emotional and mental health, they live happier and healthier.

In conclusion, I'd like to say that we as mental health professionals have a great role to play in promoting the mental health of women in our society. Why wait for them to succumb to various psychiatric disorders and then come to us for help? Let us engage proactively to enable them to assert themselves. I'd like to end this piece with a quote of Steven Aitchison : *Emotional pain is not something that should be hidden away and never spoken about. There is truth in your pain, there is growth in your pain, but only if it is first brought out into the open.*

From Our Guest Writer...

A different kind of love

Kalpana Karunakaran

Kalpana Karunakaran lives in Chennai. She has an MA in History from Jawaharlal Nehru University (JNU), New Delhi, and a Ph.D. from the Madras Institute of Development Studies (MIDS), Chennai. As an activist with the People's Science Movements, Kalpana has many years of experience organizing women's self help groups and right to health campaigns. Currently, she works as faculty in the Department of Humanities and Social Sciences, IIT Madras. Her teaching and research interests are in the domain of development studies with a focus on gender and women's studies. The paper below was originally brought out by the Indian Cultural Forum and has been reproduced here with minor editing alterations with their kind permission.

On 25th November 2016, when I heard that the Cuban revolutionary and national leader Fidel Castro had died, I rushed to my ailing mother's bedside with the news. In 1968, an intrepid young woman of 28, my mother Mythily Sivaraman, a socialist and anti-imperialist, had made a clandestine visit to Cuba from the US where she was then living and working. In the years that followed, she wrote frequently of the

spirit of the Cuban revolution and its determination to endure in the face of the behemoth that opposed it. When I conveyed the news of Castro's passing to my mother, I did it because I could not contain myself. I did not expect that it would make a difference to her. By then, she was in an advanced stage of Alzheimer's Dementia and had lost memory, speech and mobility. She recognised neither her husband, nor her daughter.

And yet, when she heard that Castro was no more, her eyes shut tight, filled with tears. She turned her head away and refused to look at me.

That my mother reacted as she did should not have surprised me. It spoke of the way she had lived her politics. A trade unionist, feminist and communist, my mother's affective universe, constructed through a life-time of principled political action, extended well beyond the confines of family, kith and kin. For over a decade, my father and I were care-givers of a woman who cared a great deal about the world. Today, I have taken the opportunity to reflect on caring in the light of larger debates about how we, as humans, may create cultures of 'conviviality' where neighbours, strangers, neighbourhoods and communities live together, while "engaging with, confronting and embracing differences" (Adloff, 2019). How may we retain our distinctive singularity and strive for recognition, without slaughtering each other? A palpable concern that runs through the Convivialist Manifestos is the vexed question of how to foster and build on our mutual interdependence founded on a full recognition of each person's humanity and dignity (Convivialist International, 2020).

The context of care-giving that binds vulnerable persons and others (individuals or institutions) together, fraught with unequal dynamics between the giver and the receiver (of care), may provide a useful vantage point to examine this. How may the dignity and humanity of those debilitated by incapacitating illnesses (physical or psychosocial) be foregrounded in the social relationships that surround care-giving? How does caring for the world or caring for a loved one transform us and what questions does it lead us to ask of our institutions and ourselves?

A good place to begin would be to understand what 'caring' meant to my mother. Building rich relationships with a multitude of people across castes and classes, she had forged an intensely political ethic of care. For her, being political meant never looking away from human suffering and always seeking to heed it. Reflecting on the subjectivities that animate resistant political action in the contemporary world, the philosophers Michael Hardt and Antonio Negri (2004) argue that the modern conception of love limits it almost exclusively to the bourgeois couple and the claustrophobic nuclear family. Against this confinement of love as a strictly private affair,

they posit an unrestrained and generous conception of love that is not a 'love of the same' or 'love of those like yourself'. In doing this, Hardt and Negri allude to the transformative potential of an inclusive, democratic form of 'love as politics' and its radical possibilities in serving as the basis for our cherished political projects and the construction of a new society. "Without this love, we are nothing", they write (*ibid*).

In retrospect, I can see that it was a form of 'love as politics' that informed my mother's commitments. It enabled her also to re-work, in part, domestic life and the dynamics of her household. Our house was always open to her friends and associates, party comrades and others, often showing up late night and staying over to talk. Holding forth with conviction, she was the centre of lively discussions and arguments debating politics and the public interest. Women fleeing abusive husbands knocked our door at night sometimes. In the poorer colonies adjacent to our neighbourhood, many knew of my mother as a Communist leader, who could be approached for help at short notice, such as Nagammal, from a peasant household in Villupuram district, who would show up early mornings, carrying her yellow cloth bag, in order to discuss how to bring to book the policemen and their accomplices who had illegally detained and brutally tortured her in police custody. While my mother's political activism was anchored within the mass organisations that she was part of (National Vice-President of the All India Democratic Women's Association (AIDWA) and a full-time member of the Communist Party of India-Marxist), being a communist and a feminist were, above all else, an ethical way of being for her.

The intensity of being that struck almost anyone who met her manifested in ways that harmed her too. Her bouts of illnesses that I witnessed as a young girl, involving severe migraines, recurring gut infections, undiagnosed body pains and allergies, alarmed me. In her case, as I came to see much later, the boundaries that separated the self from the world were porous, with one easily bleeding into the other. I would like to quote from an essay 'My mother, Comrade Mythily' that I wrote in 2015:

Anti-depressants (medication) did help from the mid-1990s. The immediate effect was dramatic and they seemed to have bought her time.....I was shocked to discover that the mind could impact the body. The domain

of the mind was not something my communist household had ever discussed. Do Marxists acknowledge that the mind may sometimes have sovereignty over the body?

It was in 1995 that I heard of 'clinical depression' for the first time. Perhaps, this was the first time my mother had heard it too. She did not immediately seek to understand her condition better, as I recall. I suspect she may have felt somewhat embarrassed to have an affliction of the mind, given the popular notion of psychosomatic illness as somehow less than real. But some years later, she began to read avidly on mental illnesses and, in particular, on feminist interrogations of the discipline of psychiatry and its construction of the 'unfeminine' woman as mentally ill. This was when she began to work on a book on the life of her maternal grandmother Subbalakshmi, a woman who would not be contented with her duties as wife or mother, preferring the company of books to that of her grandchildren. Mythily's book delved into Subbalakshmi's life – her remoteness, her withdrawal from social life, her eccentricities that made people around her think of her as mad. Through the lens of Subbalakshmi's life, Mythily asked: What is insanity? What constitutes the normal? And how are these linked to gender identity and social oppression?

Mythily addressed these troubling questions through meticulous research and with passion in her book. Nonetheless, her own health continued to deteriorate. In August 2007, we consulted NIMHANS in Bangalore after exhausting all medical options in Chennai. Her depression should not worry us, the doctors said, as much as what she had been battling unknown to us - Alzheimer's Dementia. 67 years of age (when she was diagnosed), she had crossed the early stages already. It was not only memory, but the faculties of perception, cognition, judgement, abstraction and reasoning that she would lose.

Her doctors cautioned us to not share the diagnosis with her for fear that it may worsen her depression.

For a while we agreed but eventually, this appeared pointless to me. She has a right to know, I reasoned with my father. When I finally told her, Alzheimer's was just another word that had no meaning for her. "Words are leaving me", she said to me one day.

The year 2010 was a turning point. When my father fell ill with high fever, I quarantined him and kept my mother away to protect her from infection. Disoriented by this, she began to ask me where the 'other girl' was, the 'other Kalpana' and who I was and could I please tell her who my parents were and how did I come to be in this house? Her anxious questions disappeared in a few weeks when her older sister showed her the family albums. The reprieve was temporary. Her confusion returned with renewed force some months later. This time my father bore the brunt of it. She asked where her 'real husband' was and who was this stranger who resembled him. Despite our protests, she was adamant. 'No, this is a sweet man, but not my husband', she would say. 'There are 18 men in this house who wear the same face', she said to me one day.

In May 2011, we went back to NIMHANS, seeking to understand this baffling phase of mis-recognition. Waiting to be administered the standard memory and cognitive tests in the out-patients' room, my mother was immersed in reading a paper on the Gandhi-Ambedkar debates that she had picked up at the home of the friend we were staying with in Bangalore. Her medical tests done, she came out and dramatically informed us that 'no question was asked about Gandhi or Ambedkar' after all the reading she had done! 'Look at the world from her eyes,' the family counsellor at NIMHANS said to my father and me. When each moment appeared discrete and unconnected to the other, how arbitrary the world must seem to her, I thought.

I would now like to reflect on how I responded to my mother's illness through its different phases. Initially, I felt let down by her when she could no longer be a public figure, the 'hero mother' I idolized. I was bewildered



and saddened by her metamorphosis and therefore, perhaps, less kind than I could have been. I tried often to counsel her, rather foolishly. She must take things slow, retire from public life, read novels, listen to music, stop to smell the daisies and so on. Above all, I wanted her to stop fretting that she couldn't read, write, speak, think or act as she used to. It meant, in effect, that I was telling her to stop caring about the world. But how could she? She did not know any other way of being in the world. I would say to her, now and again, that she must not blame herself, lose her self-worth or feel diminished since everyone had some form of illness, and hers were just like some other ones, say, BP or diabetes. But these facile analogies stopped making sense to me. For one thing, neither depression nor Alzheimer's felt like any other medical condition that I knew of. Sometimes they were downright terrifying.

During the peak of her confusion about my father, my mother's disorientation filled me with unease in the pit of my stomach. I experienced the familiar sensation of waking up early mornings and feeling as if I were walking alone in a valley of fear. Eventually, I found the key to understanding my mother's distress when I came upon an excellent website for Alzheimer's caregivers and wrote to its creator, describing my mother's quest for her 'real husband'. She wrote back, mentioning the 'Capgras Syndrome'. I read up everything I could find on this. In his essay, '*The Unbearable Likeness of Being*', the neuro-scientist V.S. Ramachandran lucidly describes a condition wherein the illness-afflicted brain mis-recognises a familiar person, usually a close family member, for an imposter and concocts a story to account for large gaps in one's memory. Since I understood the 'science' of it now, I hoped to make my mother see the underlying cause of her (misplaced) agony. I wrote her a letter in which I explained, as simply as I could, that she had a 'memory virus' that had eaten up her memories and, therefore, her brain was conjuring up a patently false story (that the man she married had gone away). No one had abandoned her, I wrote in my letter. It was her ailing brain that was deceiving her.

While I endeavoured to make my mother 'see' things differently, my father accepted that her sense of the world was irrevocably altered. He held her hand with tenderness when she asked him to trace the 'other man' and simply refused to heed my plea to tell her that he was the one she was looking for. I, on the other hand, told her the story of my life, hoping it would re-ignite

the embers of old memories. My efforts accomplished nothing. I felt emptied out and weak at the end of each telling. I also came to see that truth, of the absolute, merciless sort could hurt her. Fortunately, I found a paper written by a professor of religion on her experience of caring for her mother with Alzheimer's. Gisela Webb (2001) urges that care-givers practice compassionate speech which involves not the bland statement of an objective truth (such as 'your parents are dead'), but the choice of the words least likely to inflict pain. As she puts it, when caring for someone with Alzheimer's, it is an ethical mandate to use the language that bridges the distance between the self and the other. Reading this, I came to see what my father instinctively knew. I could never get my mother to conform to my reality. I must enter hers. I was reminded of a maxim that I would use to teach the concept of 'gender' to my students: '*What the mind does not know, the eye cannot see*'.

Even as my anxieties lessened, my mother moved to a different phase. The need to locate herself with regard to time, space and social relationships, ferocious in its intensity while it lasted, evaporated. She was always one step ahead of us. She would change even while we were struggling to keep pace with her needs and her state of mind. She kept us on our toes. In her new state of being, she was curious, alive in the moment and joyful. She still did not know us, but it mattered little. Mercifully, she no longer sought to know us in that terrible, desperate way. She took to addressing my father, in turns, as *appa*, *thatha*, comrade, even 'you man!' I said to my father, 'How much she loves us, not even knowing who we are'. Forgetting the customary use of everyday items such as combs, pens and tooth brushes, she was endlessly inventive in the alternate uses to which they could be put, as my father would observe with delight. She would hide our mobile phones and it became a game for us to find them.

She was keen to go out and see places, meet people. Any meeting my father attended, she would demand to know with indignation why she could not go with him. 'Are girls not allowed? Only boys then!', she would exclaim. Reading a 'nature' piece in the *Frontline* magazine once, she found a reference to the Sambar deer. She read aloud each sentence laughing enough to burst a gut. I realized that she thought that it was the South Indian Sambar dish that was prancing about, agile and fleet-footed! Even though words were leaving her, she deployed those that she had with creativity. In her

bedroom, she had a mosquito net that was tied to the four ends of the bed with different-coloured ribbons. She first forgot the complex knotting arrangements and then the word for 'that which falls over our heads like a waterfall'. Looking at the world from her eyes, I lost my fear of my mother's 'madness'. Allowing her to lead, I let myself go, so that I could be with her in that magic space, without history or memory or the urgent concerns of the present.

Rather than tell her the story of my life, I began to tell myself the story of hers. She may not know me, but I was determined to know her in ways I simply did not earlier. Pushed by the historian and writer V. Geetha, I began to gather my mother's writings from the late 1960s, the start of her political life. At the book launch of her collection of essays in Chennai in 2013, I witnessed first-hand the tidal wave of deep affection and respect that her comrades and friends from her party and other social movements had for my mother. This was the legacy of the 'love as politics' that my mother had nurtured over her lifetime. Over the decade and a half of her illness and withdrawal from public life, my father and I were conscious that we may be her primary care-givers, but we had no exclusive rights over her. We were accountable, in a sense, for her well-being to a wider public that sorely missed her and felt her absence.

Over the years, when addressing her comrades' queries and concerns about her health, I found that I had no easy recourse to a language by which I could describe what she (or we) were going through. I was asked more than once, 'Did she think too much? Write too much? Tire out an organ that could have been used

more sparingly?'. I would try to explain the death of the brain in Alzheimer's and how it was not the usual forgetfulness associated with ageing. Neither was clinical depression a phase of sadness, I would add. And further, chronic depression itself over a long period of time could actively harm and even shrink the brain. My mother's comrades struggled to make sense of her debilitating decline in a context of little or no public understanding of or communication around neurocognitive or psychosomatic conditions. Our home was always open to her friends and comrades who wished to see her. 'You must know that she may not recognise you', I would warn them in advance to save them from confusion. 'Oh, Comrade Mythily will always know me!', some would cheerfully counter.

In the later stages, when she was bedridden and mostly unresponsive, her friends from the women's organisation that she had led would sing 'movement' songs and exhort her to join them again in the world of *manadu*, *porattam*, *mariyal* (conference, struggle, gherao). I continued to share her pictures and images on Facebook, where many of her former co-workers and comrades could see them. When her friends asked if they could take photographs with her and share them, I agreed. Was I exposing her? Perhaps I was. But I felt that she must not hide and she must not be hidden. And her care-giving was a large part of my life, my every day. If I hid her, I would have to hide myself too. And, thus, we co-created a community that cared for Mythily, who cared so deeply about the world. This community of carers kept the vigil with us till the end. I continue to marvel at the generosity of this incandescent love. Without this love, we are nothing.



A workshop for children by students of Psychiatric Social Work. Another example of the scope of PSW. Photo courtesy: Dr. Aravind Raj, PSW faculty at NIMHANS and member of APSWP

Journey of a Psychiatric Social Worker from Textbooks to the Field

By Sreepriya Menon

Sreepriya Menon is an alumna of Lady Sriram College (LSR), Delhi University, the Tata Institute of Social Sciences (TISS), Mumbai, and the National Institute of Mental Health and Neuro Sciences (NIMHANS), Bengaluru. She is one of the Co founders of SWARI Foundation and its HR Head. She works with individuals, families, and organizations on mental health issues and user rights in the community. She also is the founder of The Good People Diaries which is an online platform to highlight positive news within the social sector. She participates in public events to raise awareness about mental health issues of various groups. She started OSTEM (Online Support Team for Every Mind) in March 2020 with her colleagues and volunteers to address the gap between mental health service users and providers during the pandemic via online platforms and to enable user participation in this process. She is also a practising therapist.

Professional Social Work networks have been the strength of the communities that they work for and represent across contexts in the world. The degree to which they are representative of the people's needs and concerns and the degree to which they make their organizational and administrative processes participative and inclusive of the community members decide the efficacy of the interventions they implement and their desired changes in the larger society. One of the key challenges faced by social work professionals is that of communicating within and across their own and allied professional groups. Having a rich theoretical understanding to social problems is our strength; the differences we may have in terms of ideologies, approaches, programmes, and implementation methods need not divide us, rather, they can further enrich and strengthen.

The idealism that accompanies a student as they learn excitedly about the scope of a social worker's job immediately plummets as they step into the field because the stark reality of limited resources, oppressed voices and corrupt systems scars them. Were these realities not evident to the student during course work, since both Social Work in general and Psychiatric Social Work in particular include hundreds of hours of practical field work? The fact is that working on pre-designed programmes under the multiple protections of supervision and guidance of both the teaching institution and the placement agency, the student is mostly insulated from ideological battles as well

as the responsibility to take decisions and face their consequences. With these umbrellas folded up and put away, the graduating student is confronted with responsibilities that are not evaluated through marks but carry consequences engaging and impacting others as well. Idealism is put to test and battle wounds can happen. I believe now that both the idealism and the scarring are necessary graduation milestones for all social workers. The peers I have spoken to at various points of my journey during and after my training have reflected the feelings that often go unexpressed by social workers – the frustration, the lack of money, the experience of not being understood by family or peers or other professionals, the isolation resulting from trying to work with systems that do not respond very easily to change, the feeling of being under-informed but overqualified, the insecurities about one's own future and, of course, all of this contributing to some amount of burnout and sometimes, ill health. Social work is not an automatically remunerative area of work. At the end of obtaining three degrees in higher education, a Psychiatric Social Worker is still confused with a 'do-good politician' or worse, not understood clearly by role even within a mental health team. I have passed through such an ordeal-by-fire myself. Now, when I see colleagues and friends winning their fights and moving ahead in their journeys I feel proud. While someone is teaching social work to eager trainees, others are taking up training and public speaking, someone is advising in policy and reform, while some are bringing the nuance of social work perspectives and inclusion into other fields

where traditionally there has been marginalization.

As a person with an M.Phil. in Psychiatric Social Work, my joy and experience of working with diverse professionals led to the birth of WorkAble, a psychosocial and rehabilitation initiative under SWARI Foundation. SWARI stands for Silk and Woodarts Research Institute. Started with the objective of reaching the works of rural-based silk and wood artisans to urban and international markets, SWARI has been working closely with the crafts people of Ramanagaram and Channapatna areas of Karnataka State. The picture alongside has been sourced from SWARI and shows tops made of wood, as part of the repertoire of toys and other artefacts. WorkAble was started in 2021 and partnered with SWARI to make programmes more inclusive of people with disabilities, including people grappling with psychosocial problems and mental health issues.



- We organized events that brought together professionals from the fields of social work, education, gender rights advocacy, users of mental health services, caregivers, teachers, students and members from the SWARI team to spare some time discussing and learning from each other's experiences from the field.
- We partnered with colleges and high schools to involve students of mental health based courses to tell them about various government and non-government initiatives in research, policy, and rehabilitation work going on at multiple levels in the country.
- Following from the positive response from the students, we carried out an online programme about challenges in employment and sustaining livelihoods of persons with psychosocial disabilities, with experienced speakers from the field.
- We put together a discussion on 'Communalism and its impact on persons with psychosocial disabilities' in the light of tensions felt by people across the country. We had thoughts from persons with disabilities, NGO representatives, and educationists about how communalism had entered even classrooms and higher academic institutions.

The links to these programmes can be found on the SWARI YouTube channel under WorkAble, but for ready reference, they are <https://youtu.be/7u8j1jvTnHE> and <https://youtu.be/Thk1DbPdvq0>

Our collaboration with the Psychiatric Rehabilitation Services of NIMHANS was made possible due to the help and support we received from Dr. Aarti Jagannathan, Consultant in Psychiatric Social Work, NIMHANS, and the team of staff there in involved in psychiatric rehabilitation services. With this link we have been able to support the transition of some patients from hospital based vocational activities to community based employment. In the process of creating a database of people with psychosocial disabilities looking for jobs who come with their diverse skill sets, and advocating for their placement in their corresponding interest areas, we have learned a lot. We have learned that building

a relationship with the client, their caregiver, and their employer helps in making the ecosystem where they would be working truly inclusive in spirit. This includes sensitizing the employer about specific strengths and challenges of working with this client, incentivizing their attempts at being inclusive and at the same time, sensitizing the client and the caregiver about the needs, demands, and pressures of the market. This also includes reassuring the caregiver, encouraging the client, and convincing the employer to believe in people rather than giving into their worries. Giving and receiving due feedback with all concerned on the process completes the loop.

The WorkAble Team started off as 'outsiders' in comparison to the SWARI Team that had a longer history of working with the silk and woodwork artisans of Ramanagaram and Channapatna. But as we increased our interactions and established ourselves as genuinely rooted, we gained acceptance and hence, it was as 'insiders' that we were able to get an understanding of the ways in which the local people were marginalized, stemming from a variety of causes including poverty, limited access to information, no formal education, absence of adequate access to affordable health care and other entitlements, the need to come to terms with

the ubiquitous presence of corruption in dealing with the Government, and all of the above compounded with gender inequalities and minority religious identity. These were their lived realities; we now understood them much better from within. And ironically enough, our 'insider' status meant that our team now also had to battle the challenges of being marginalized. We coped because our strengths and hopes came from the field – from the people we lost to Covid from our team, from taking care of families, from supporting marriages of people who made their own choices, from paying children's school fees so that their formal educational journey would not be cut short, from organizing and participating in cultural activities, and from celebrating all religious festivals together with the local communities. Expanding out now, we collaborate with the Online Support Team for Every Mind, Scleroderma India, The Good People Diaries, Project Empathy from Reachout Foundation to talk about inclusion, education, mental health, employment and stories of positive change with everyone. We coordinate for internship opportunities, link people to mental health and other public/government services, facilitate documentation for PwD and the elderly at the State and District level, have undertaken fundraising campaigns for food security, educational aid, business proposal meetings, and hearing out people.

We attempt to foster innovation in designing social work solutions for real world problems by making use of the community's understanding of what their concerns are, and how best to integrate their approach with the theoretical and evidence based approach that we learned about in our social work training. This pushes our understanding and empathy beyond the textbook

SWARI PRESENTS

Online Workable Meet Up!

// 19 DEC
Sunday
04 pm – 06 pm

LIVE

THE SPEAKERS

- Girepriya Menon**
Host
- Ajit Babu**
Co-Host
- Dr. Anita Rego**
Director
Pearless4development
- Shruthi Mohan**
Independent Journalist
- Anindita Biswas**
Queer & Dalit Affirmative
Social Worker

OUR OTHER ESTEEMED SPEAKERS

- Shobhitha**
We are your Voice
- Shanthi Muniswamy**
Aravani Art Project
- Dr. Arun S**
Asst Prof, Sampurna
Montfort College

WorkAble-2021 Psychosocial Disabilities in Workspaces

The event and discussion is a celebration of neuro diversity and a confluence of diverse perspectives on collective and inclusive development.

To know more visit
www.swari.org
FB/SWARIFOUNDATION

to be able to “see” the people we are working with on the ground as people and not just “beneficiaries” or the “oppressed”. The hierarchy of power between the social worker and the community has to be minimal because, in this aspect, ours is a unique profession. We can ally with the people we work much more than other service professionals. We have to celebrate that; we have to leverage from that.

Know Your Concepts

Exploding Head Syndrome

Experienced since time immemorial, documented since the 1870s, and named and described in a clinically detailed manner in 1989 by British neurologist John M.S. Pearce, Exploding Head Syndrome has been called a 'partial hallucination' occurring in the state between sleep and wakefulness and involving the sensation of a loud exploding sound in the head. Very occasionally, flashes of light have also been reported. It is believed to be a harmless condition causing no pain but significant fright. Possible causes include sleep deprivation and/or high levels of stress and anxiety. Reassurance and Talk Therapy are usually adequate treatment.

WE CONCLUDE WITH

How diseases are born

(Author unknown. Received as a WhatsApp Forward from the Facebook page of Jagruth)

"Silence your tears"
"Swallow 'the bitter pill'
"Shut your mouth!"
"Silence your heart"

But the body speaks, oh does it speak!

It speaks through the fingers, tapping on the table surface
It speaks through restless feet in bed
It speaks through a nasty headache
It speaks through gastritis, reflux, and anxiety
It speaks through a knot in your throat
It speaks through anguish and a wrinkle on the forehead
It speaks through insomnia or too much sleeping.

You might silence your voice but the inner dialogue begins...
People get ill because they harbour and keep undigested issues in their hearts.

Expression soothes the soul!
Pain isn't meant to be lived forever;
Pain is only a comma!

So write a letter, a poem, a book.
Sing a song.
Pick up your shoes and tap dance.
Make a joke, create a text, paint a canvas, meet with your friends, even if it has to be virtual...
Jog in the park.
Speak with your therapist.
Converse with God if you believe in one.
Be an Artist!
Talk to yourself, to your puppy,
Scream to the Heavens,

BUT DON'T BE SILENCED!!

Because if you swallow everything that you feel, you will end up drowning!

THE HEART IS NOT A WAREHOUSE.
And the body speaks!

*Dying to say something relevant to psychosocial care?
Say it here! Write for the APSWP Newsletter!*