

How to Help Tina?

SDM in people with dementia



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Outline

- Case intro
- Introduction to dementia
- Introduction to the Betreuer system in Germany & Taiwan
- Problems to solve
- Solutions
- Conclusion



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Case Intro

What's wrong with Tina





Tina W. with dementia is fiercely independent. Above all, she insisted upon remaining in her own home. She believed she could cope without assistance, and refused to admit carers. In fact, only with such care could she be sustained in her own home. Her son sought a court order. Tina W. declared that she much loved her son, but did not need a representative and did not wish him to be appointed. The son was appointed as a Betreuer with powers to ensure that carers would be admitted and could properly perform their functions – or the son is appointed as an assistant, because otherwise her overriding desire to remain in her own home would not be sustainable.



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Introduction to dementia

What symptoms does it cause?





Introduction to Dementia

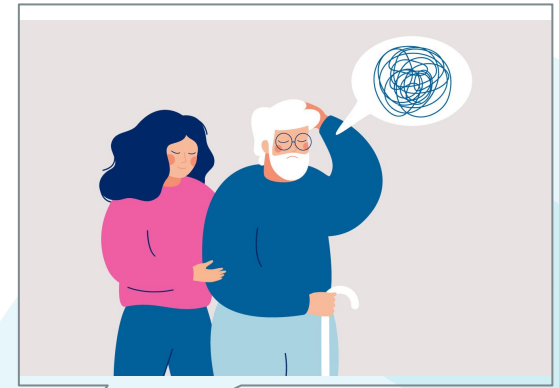
- A **syndrome** resulting from acquired brain disease; most patients are elderly
- Characterized by a **progressive** decline in memory and other cognitive domains (i.e., language, executive function, complex attention, etc.)
- When severe, it can interfere with daily life and one's independent functioning





Introduction to Dementia

- No known cause & cure for degenerative dementia
 - **Neurodegenerative**: progressive degeneration and/or death of nerve cells ***incurable**
 - symptoms associated with dementia continue to progress in severity until death
- Treatments focused on providing care and help, rather than fixing the underlying neuropathological problem



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Introduction to the Betreuer System

Policy in Germany and Taiwan



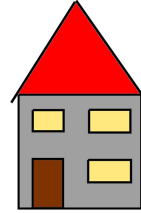
Introduction to German Betreuer System and Dementia

Equal recognition before the law

→ §1896 BGB appointment of a Betreuer:

- Dementia → mental disabilities
- Necessity
 - The Betreuer may only be appointed for areas of responsibility in which the Betreuung is required
 - self-determination

→ supported decision making



Introduction to Taiwan Betreuer System and Dementia

Adult Guardianship System in Civil Code

- From Sec. 1110-1113-1
- Many restrictions, since most of the regulation is based on child guardianship
- Autonomy is seriously stripped

Senior Citizen Welfare Act (Focusing on the Generic Issues)

- Sec. 13, 14
- Obligation of government to helping the elderly apply for guardianship
- Suggestion of issuing a trust to protect property

「台灣失智症防治照護政策綱領」
專案報告

衛生福利部
102年10月9日

Introduction to Taiwan's System and Dementia

Mental Health Act

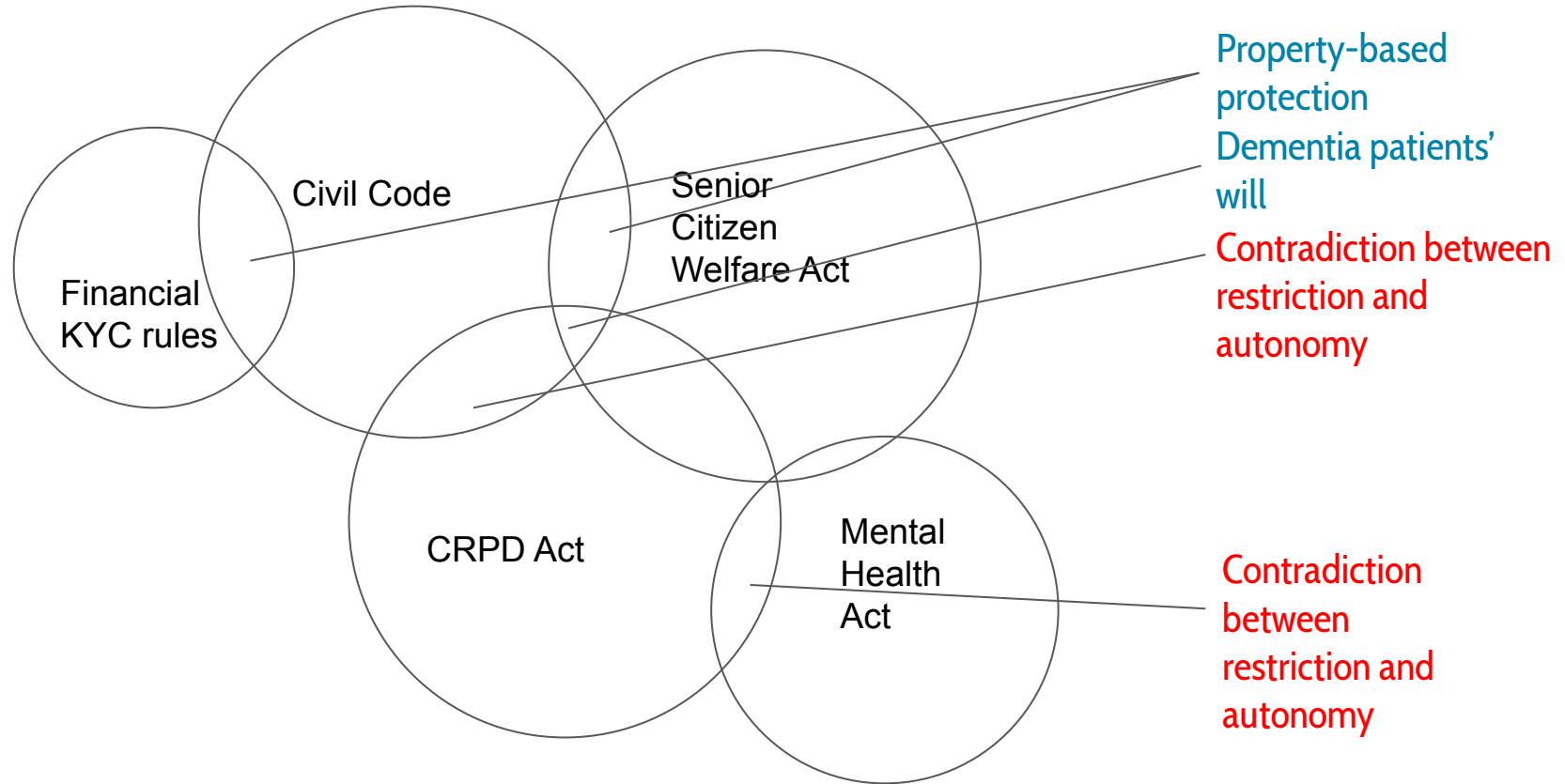
- Not really focused on dementia
- Compulsory medication: only in very serious conditions

Act to Implement CRPD

- Introducing CRPD to Taiwan legal system
- Providing principles of human-centered SDM
- Contradiction with MHA / Civil Code



Framework and Interaction



Our Goal

We want to trace back Tina's past decisions (biography) when it comes to helping her making decision.



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Problems to solve

What are the problems we have?





Problems to Be Solved

- Communication Barrier
- Emotional issues
- People not familiar with the Betreuer system
- Reluctance to receive help
- Conflicts between the patient's will and the situation





Communication Barrier

Problem:

Due to dementia, Tina may not be able to **build mutual understanding** with us, and there may be a gap between what she knows and what we know.

Possible Solutions:

- Utilize **tools** e.g. translator, simplified language, pictures
- Seek **help from others** who are able to communicate with the patient / people who the patient trusts (e.g. close family members / friends)
- Look into Tina's **biography** to understand how she makes decisions and what she values





Communication Barrier

Possible Result:

We meet Tina and her son. Thanks to **her son's help**, and by using some tools (e.g. **pictures and diary**) to understand Tina's mind, and some other records that show how she usually reacts in the face of legal problems, as well as by **interviewing Tina's best friend**, we may successfully help Tina understand the tasks of a legal guardian, and piece together Tina's true will.





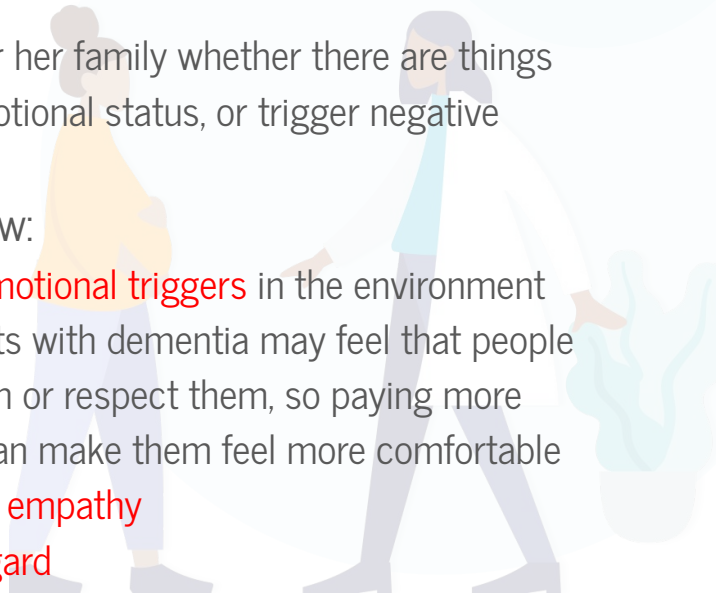
Emotional Issues

Problem:

Due to dementia, Tina may undergo serious **emotional fluctuations**, which can make her easily distracted from the meetup and discussion.

Possible Solutions:

- Before the interview :
 - **Double-check** with Tina or her family whether there are things that may affect Tina's emotional status, or trigger negative responses
- During and after the interview:
 - Make sure there are no **emotional triggers** in the environment
 - Be a **good listener**: patients with dementia may feel that people do not often listen to them or respect them, so paying more attention to their words can make them feel more comfortable
 - Person-centred approach: **empathy**
 - Unconditional **positive regard**





Emotional Issues

Possible Results:

During the first several meetups, Tina usually gets irritated or frightened due to her dementia.

However, we start to check with her family about her condition, and remove the possible emotional triggers before meetings, and the situation gets better afterwards, with the discussion not interrupted so frequently. Throughout the conversation we treat Tina with respect and act emphatically, patiently and with positive regard.





Unfamiliarity with the Betreuer System

Problems:

Tina's son, originally appointed to be Tina's Betreuer, is **unfamiliar** with what a Betreuer should do, and he also has some misunderstandings about the Betreuer system. **Tina doesn't understand the Betreuer system as well**, and that's part of the reason why Tina doesn't want to get a Betreuer.

Possible Solutions for Tina's son

Have a person with professional knowledge be the betreuer (Japan)

Make the family member eligible

- Offer courses and resources to help Tina's son understand the Betreuer system
- Provide legal, psychological counselors to help Tina's son

Possible Solutions for Tina

Use brochures, placards, pictures and videos to help Tina understand the system

Provide a **hotline** for Tina once she has problems or questions to ask

Explain **the legal basis** and make the complaints system accessible to Tina (Court)

Prepare **reminders** that point to all the things she needs to know (dementia)



Unfamiliarity with the Betreuer System

Possible Results:

With the help of courses and counselors, Tina's son is enriched with the knowledge of the Betreuer system. He is also confident that he can do the job well. After a social worker and counselor visited and explained the system to Tina, she is more familiar with the Betreuer system and also understands how to file a complaint if her right is harmed under the Betreuer system.





Reluctance to receive help

Problem:

Although Tina has shown very evident symptoms of dementia, she still denies her disease and refuses to get help.

Possible Solutions:

Ask the patient if he/she has any physical or mental discomfort and take him/her to the doctor whose speciality is **related to the symptom he/she stated**

→ Ensure the patient feels that people care about what he/she feels

→ Let relevant authorities (e.g. doctor) release the fact that the patient needs external help for his/her **symptoms**

Avoid negative expressions of the patient's perceivable symptoms

→ e.g. Don't say "You're old and forgetting everything!" when the patient forgets something that seems simple or normal.



Reluctance to receive help

Possible Results:

Tina originally kept denying her disease. But after Tina's son brought Tina to the hospital to meet the doctor whom Tina is familiar with and trusts, and with suggestions from her close friend, she gradually accepted her situation and stopped denying that she has a condition.





Conflict between the patient's will and the current situation

Problem:

Tina does not want to give up her home, she refuses any external offers of help.

Possibilities to find a solution pertaining to Tina's will could be:

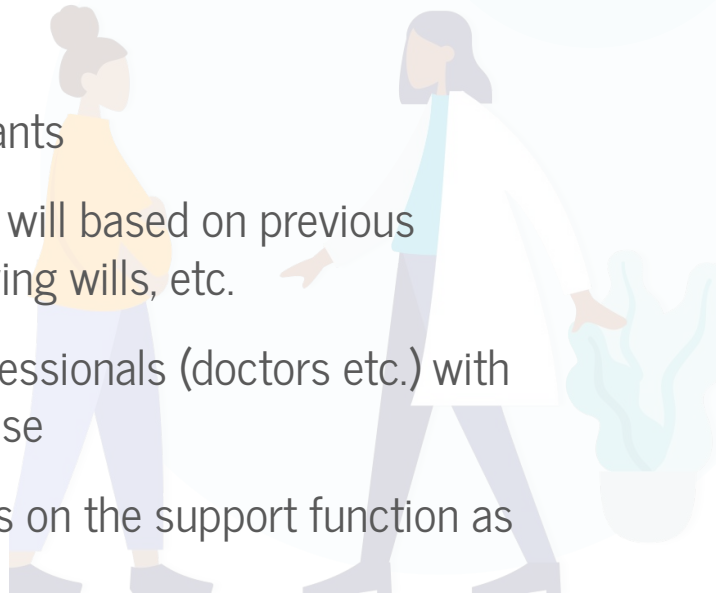
Question the patient's own will

Support from the patient's confidants

Conclude about the patient's own will based on previous decisions/ documents such as living wills, etc.

Support from/ connection to professionals (doctors etc.) with regard to understanding the disease

Appreciative interaction; emphasis on the support function as legal guardians





Conflict between the patient's will and the current situation

Possible Results:

After being counseled, educated and supported in her decision-making by professionals as well as friends and family members, Tina agreed with her son to continue living in her home but to install some supportive measures, such as a carer who will move to Tina's house to support her. Tina's son is appointed as legal guardian. Furthermore Tina will stay in contact with a social worker who will track her condition frequently and will install further measures when necessary. Tina was also informed about possible hotlines and counselling centres that could give her information and support in case of questions or problems.





Conclusion

- Dementia can have a negative impact on supported decision making, but the impact can be neutralised.
- The patient may be reluctant to receive help, but conversation contributes more than forcing and humiliating.
- Person-centred interviewing (congruence, empathy, respect) (C. Rogers)
- Patience, respecting a patient's dignity and will, as well as trusting that he/she deserves autonomy is the core value to deal with the problem.





Conclusion

- Uncertainty about the care system can be a problem on the part of the person being cared for as well as the caregiver. This requires education and training on both sides.
- Acting in accordance with the patient's will poses many challenges, especially in practice. It requires interdisciplinary cooperation, respect for the patient's will and awareness of possible changes (legal basis, disease development, decisions)





Q&A

- Q: Does the cultural difference influence the solutions applied to this case? Like in Taiwan, the elderly are not easily persuaded by the descendants?
- A: It does. That's why we resort to professionals to help persuade the elderly members of our family. It can also **avoid potential risk** of over-emotional conversations that might lead to humiliation or conflict.





Q&A

- Q: How should a judge reach a verdict when it comes to this case, with the conflict between the patient's will and the real situation?
- A: We should take the **patient's will** as the first priority, while there must be some limitation to strike a balance between the self-willingness and the best interest of a patient (sometimes they conflict). We think it is more proper to decide based on two criteria - whether the patient's will will **threaten the patient's health and safety**, and whether the patient's will will **jeopardise others' safety** (public interest). If either condition is met, then we shall set a boundary for the patient's will. Of course, what other limitations should be in place can be further discussed.



References

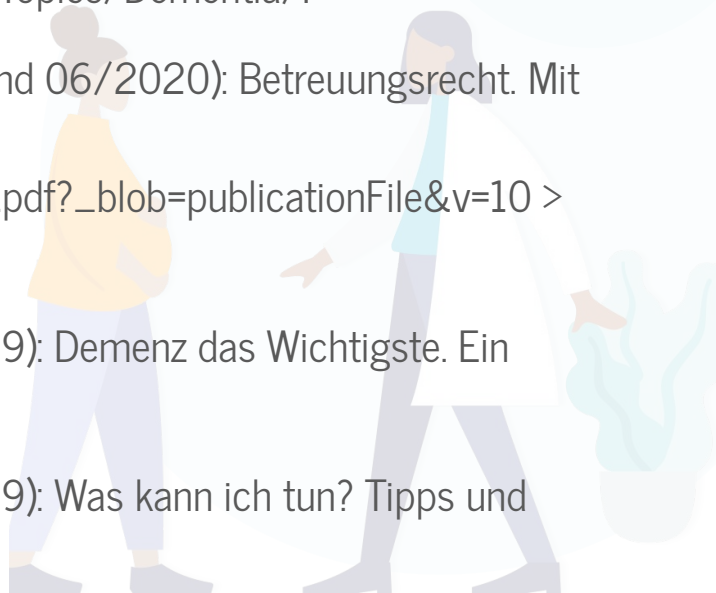
American Speech-Language-Hearing Association (n.d.). Dementia (Practice Portal). Retrieved May, 26th, 2021, from www.asha.org/Practice-Portal/Clinical-Topics/Dementia/.

Bundesministerium der Justiz und für Verbraucherschutz. (Stand 06/2020): Betreuungsrecht. Mit ausführlichen Informationen zur Vorsorgevollmacht.

www.bmjbv.de/SharedDocs/Publikation/DE/Betreuungsrecht.pdf?_blob=publicationFile&v=10 > Berlin.

Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz. (2019): Demenz das Wichtigste. Ein kompletter Ratgeber. 8. Auflage. Berlin

Deutsche Alzheimer Gesellschaft e.V. Selbsthilfe Demenz. (2019): Was kann ich tun? Tipps und Informationen bei beginnender Demenz. 7. Auflage. Berlin





References

Related Regulation, Collected by Taiwan Dementia Society (TDS), last visited in 6/11 /2021,
http://www.tds.org.tw/ap/link_list.aspx?bid=40

Civil Code, Law and Regulation Database of ROC, last visited in 6/11 /2021,
<https://law.moj.gov.tw/LawClass/LawAll.aspx?pcode=B0000001>

Act to Implement CRPD, Law and Regulation Database of ROC, last visited in 6/11 /2021
<https://law.moj.gov.tw/LawClass/LawAll.aspx?pcode=D0050194>

Mental Health Act , Law and Regulation Database of ROC, last visited in 6/11 /2021
<https://law.moj.gov.tw/LawClass/LawAll.aspx?pcode=L0020030>

Senior Citizen Welfare Act , Law and Regulation Database of ROC, last visited in 6/11 /2021
<https://law.moj.gov.tw/LawClass/LawAll.aspx?pcode=D0050037>