The background of the entire page is a lush green fern leaf pattern. An orange rectangular block is positioned in the upper left corner, containing the title text.

Living Well

With Brain Cancer

COGNITIVE STRATEGIES



UCSF Brain Tumor
Center

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Foreword

Cognitive changes are common and distressing for individuals and caregivers of those with brain cancer.

While cognitive changes are common in brain cancer, there is little information and few services available to manage these unique challenges. The Sheri Sobrato Brain Cancer Survivorship Program within the University of California, San Francisco (UCSF) Neuro-Oncology department envisions a future in which patients with brain cancer can easily access tools, support and information they need to manage their cognitive changes to continue to live a full and satisfying life. We recognize that pursuing and adopting strategies for cognitive wellness can foster greater empowerment and enhanced quality of life. We appreciate your interest and hope the information we provide is useful.

The evidenced based strategies and tips outlined here are endorsed by our UCSF Neurocognitive Services experts as well as by individuals with brain cancer. This booklet was developed as part of a special collaboration between the UCSF Neurocognitive Services and the UCSF Patient Education Sheet Thriver Advisors (PESTAs). We are grateful to our amazing PESTAs for generously sharing their wisdom and this booklet would not have been possible without their dedication.

This booklet offers both broad approaches to cognitive wellness and specific compensatory strategies for managing symptoms such as forgetfulness, distractibility, and more. Each section in this booklet is organized by 'hot topics' for managing cognitive symptoms in the context of brain cancer. The suggested tips and exercises can be done at your own pace, in your own time, and within your own abilities.

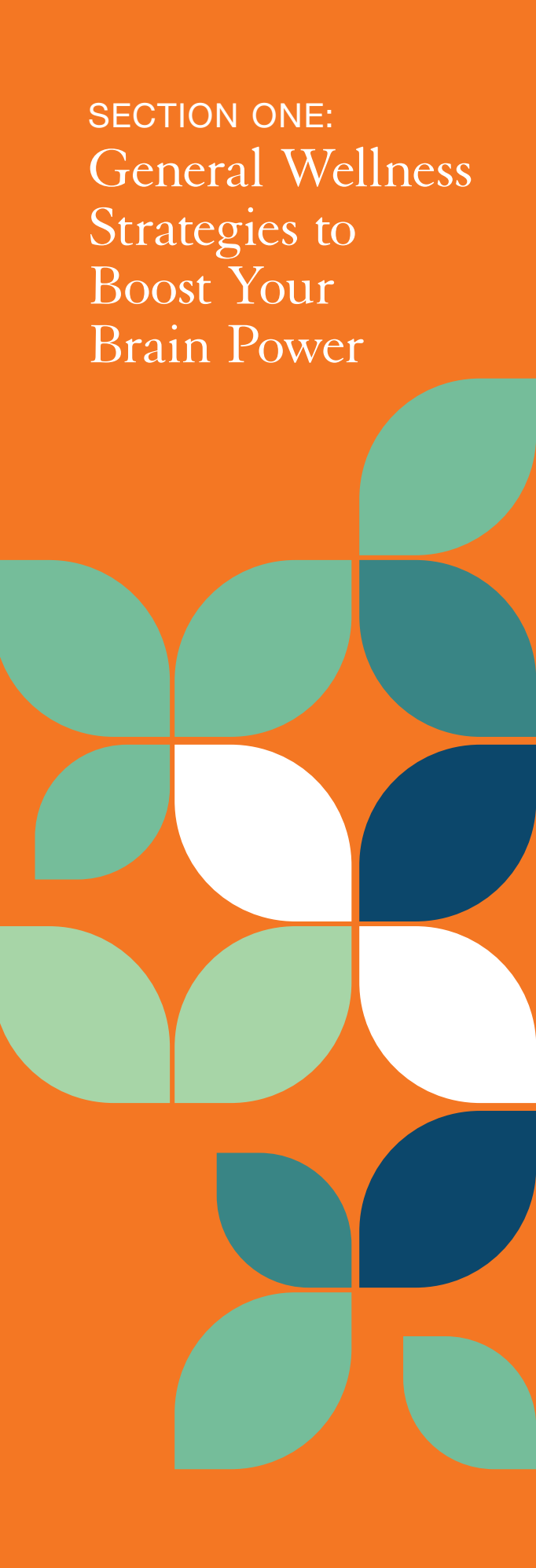
When starting to use this booklet, we encourage you to begin with tracking situations whereby you are experiencing the most distressing cognitive problems. For example, if you notice that you have more forgetfulness when you are tired, then consider starting with the section on *Managing Cognitive Fatigue* (pages 4–6). By starting to understand and problem solve more challenging situations, you can begin to feel better more quickly. We sometimes find that people can be so excited to learn new strategies that they can be tempted to try too many things at once. Unfortunately, this can lead to stopping before gaining true benefit due to feelings of overwhelm and frustration. Instead, kindly consider which suggestions in the enclosed information is most applicable to your situation and try them one at a time. Once you have mastered a skill, then move onto the next. Also, others can also be a good source of information and support if you are feeling overwhelmed or frustrated. Understandably, what works for some may not work for you, but on the other hand learning what doesn't work for you is just as important as knowing what does. Approaching cognitive wellness with a spirit of self-compassion, openness to input from others, perseverance, and focus on progress rather than perfection are key ingredients toward success.

We hope that you will find these suggestions useful. For additional support, please discuss with your healthcare team and reach out to others living with brain cancer through our UCSF Neuro-Oncology Survivors' Peer Support Program.

Wishing you cognitive health and well-being,

***The Sheri Sobrato Brain Cancer
Survivorship Team***

SECTION ONE: General Wellness Strategies to Boost Your Brain Power



Our brain is an oxygen-rich organ and therefore dependent upon a well-functioning circulatory and respiratory system. Therefore, activities that improve your overall physical wellness will also have benefits to your brain. Here are some general wellness strategies that survivors have found helpful to support their brain functioning:

Physical activity

Exercise is a good way to stay physically fit and is helpful for your brain health and mood. Physical activity can improve thinking speed, memory, learning and executive functioning skills. It also helps to support healthy brain function and reduce stress. Just 20 minutes of low to moderate intensity exercise a couple of times a week can make a big difference. Walking, yoga, gardening, bike riding, swimming and other activities are examples of physical activity.

Mental activity and novelty

Exercising the mind also helps to protect and improve cognitive function. Try to engage in activities that are intellectually stimulating and that challenge you to learn something new or unfamiliar. Arts and crafts, writing, playing games, reading, cooking, and social events can all be areas that use your mind in new and interesting ways.

Do things you love

With the burden of treatment, it can be difficult to remember to enjoy passions and hobbies. Keeping busy with things you love to do can reduce stress and keep your mind sharp. Whether it be taking a walk to enjoy nature, calling a friend, or pursuing a new passion or hobby, remember to do things that truly bring you joy and happiness.

Meaningful connection

Spending time with others, engaging in stimulating conversation, and staying in touch with family and friends are good for your brain health. Try a type of connection that works for you. Supporting others can help foster a sense of purpose. Spending time in nature has shown to improve

cognitive function, mood, and overall well-being. Walking, visiting meditation gardens, and engaging in outdoor activities are just a few ways to stay connected to nature.

Positivity and relaxation

While we all experience challenging thoughts and feelings, keeping stress in check and maintaining a positive outlook can boost your brain health and mood. Meditating, deep breathing, playing uplifting music, watching an inspiring movie, and setting realistic expectations for yourself are a few examples of ways to help your mind wind down and stay positive.

Nutrition

Lifestyle factors, such as poor diet and excessive alcohol consumption can have a negative influence on a person's cognition. Eating a well-balanced and nutritious diet rich in fruits, vegetables, and healthy fats (such as olive oil, nuts, and fish) has been shown to protect and improve cognitive function and keep the immune system healthy. If you or your loved ones are concerned about your alcohol consumption, please talk to your doctor to get information and determine the best next steps.

Sleep and rest

Getting plenty of sleep is very important for learning and memory. The average adult requires seven to nine hours of sleep per night. Skimping on a few hours of sleep or oversleeping can be problematic for your emotional and cognitive health. Maintaining a consistent sleep schedule, even on weekends, will help you fall asleep and wake up more easily. Napping is a good way to make up for lost sleep, however, napping for too long and/or too late in the day can make it difficult to fall asleep or stay asleep at night. Keep naps short, to just 10 to 20 minutes, and before 4 pm to help avoid these problems. If you or your partner notice you are loudly snoring when you sleep, then make sure to discuss this with your doctor. Please see the section on *Managing Sleep* (pages 14–15) for more information.

Routine and structure

People often feel more 'brain fog' when they don't have a good daily routine. Sticking to a daily schedule can also add purpose and focus to your day, as well as reduce the demands placed on your memory. Consider using a planner and alarms to keep you on track with your routine. Also try creating a to-do list and mark off items as you go along to track your progress.

Manage sensory and information overload


Too many distractions can overstimulate the brain and make it harder to stay focused and think clearly. To help stay focused for longer periods of time, try reducing background noises (for example, turning off nearby TV or radio), holding conversations in a quiet area, asking people to speak one at a time, and taking periodic breaks during the day to relax. See the section on *Managing Cognitive Fatigue* (pages 4–6) for more information.

Emotional Health

Emotions such as anxiety and depression can have an impact on fatigue, concentration and motivation which, in turn, can effect your ability to think clearly. Talk to your doctor about a referral to a mental health specialist if you think you may be suffering from chronic anxiety or depression.



SECTION TWO: Managing Cognitive Fatigue



Managing cognitive fatigue is one of the best places to start to improve your cognitive health. Running out of cognitive energy faster and starting off with less cognitive energy to do tasks is one of the most common side effects of brain cancer and cancer treatments. It can also have a significant impact on your quality of life.

Cognitive difficulties are made worse by the brain becoming overly tired, so it is important to address cognitive fatigue in order to begin feeling better. Here are some good ways to start to better manage your cognitive fatigue:

- **Schedule your activities and include rest breaks.** Once you have an idea of your activity limits, you can plan accordingly so you stay out of the orange and red zone. A good tool is to use a weekly planner. Space your daily activities to balance physical and mental exertion and spread them out over the week to avoid overload. This will help keep your mental energy at a consistent level.
- **Balance rest and activity.** It's important to listen to your body and find a level of cognitive activity and rest that works for you. This may need to be adjusted over time. Too much rest can actually lead to tolerating less activity and contribute to more fatigue. Use the chart on the next page to help you find your optimal balance and discover new strategies.
- **Talk to your doctor about physical exercise and what's best for you.** Counterintuitively, moderate physical exercise can often help increase physical energy and mental alertness. At UCSF, you can ask your doctor about exercise classes and services as part of your care.
- **Prioritize activities that are most important.** List your activities in order of how important they are to you, so you can do the more important ones when you have the most energy. Then reduce your planned tasks based on how much energy you have. Consider postponing and/or cancelling some of your least important activities, if possible.
- **Pace yourself and adjust energy exertion.** If you know an activity will take a lot of energy, consider doing tasks in 20- to 30-minute chunks with restful activities in-between. Take a longer rest if needed to stay out of the overexertion


zone. Look for less energy-intensive ways to perform activities, such as doing one task at a time and tackling a small piece of a larger project.

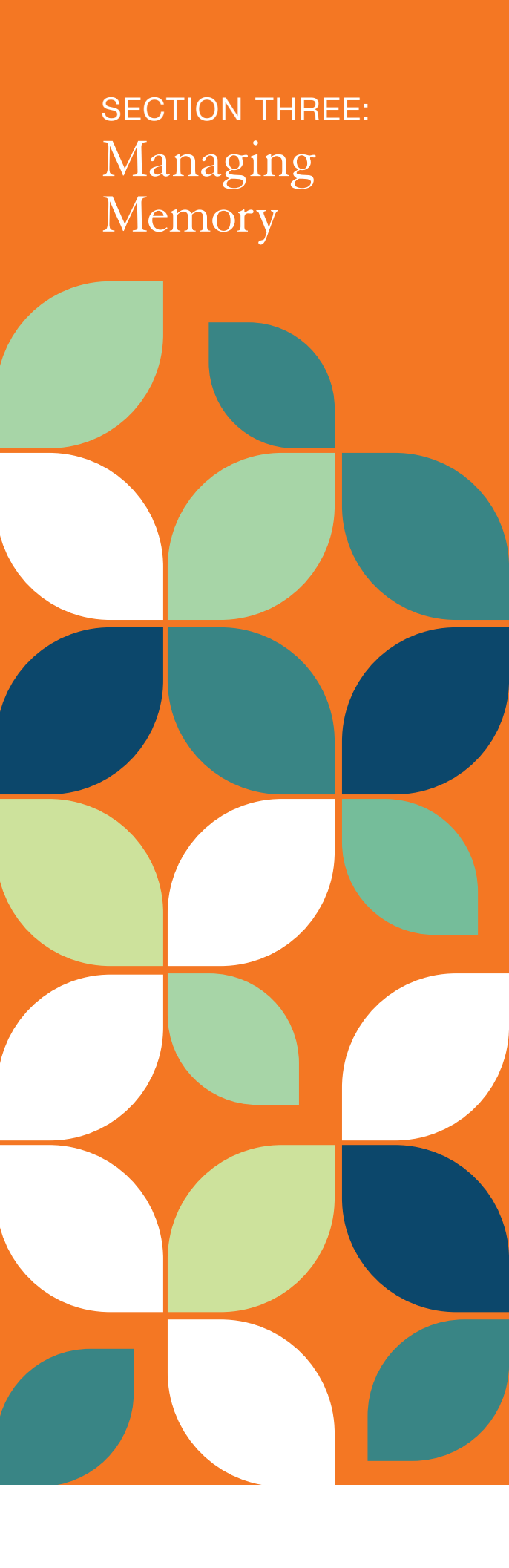
- **Delegate tasks and ask for help.** This is a time to take others up on their offers to help you. Let them unpack the groceries, fold and put away the laundry, or help you with other tasks.
- **Eat a balanced diet.** Follow physician or nutritionist recommendations and be sure to drink enough water to avoid dehydration. UCSF offers cancer patients a complementary consultation (<http://tiny.ucsf.edu/dietician>) with an oncology dietitian. You can also view our Integrative Approaches to Brain Cancer series (<http://tiny.ucsf.edu/approaches>) for more specific suggestions.
- **Engage in self-care and stress-reducing activities.** Taking in a full, deep breath throughout the day only takes a few seconds. Other activities could be meditation, prayer, talking with others, reading, listening to music, painting, or anything else you find pleasurable. You may want to set reminders to include these throughout your day.
- **Make sure to see your primary doctor to rule out any medical reasons why you might be fatigued** (i.e. low blood count, low thyroid function, respiratory cardiac limitations).
- **Still struggling with fatigue?** Try to track your energy levels and start pacing yourself sooner to prevent becoming overtired. You can think about it like a stoplight. Green is “go” — do the things you want to do. Yellow is “yield” — you are running out of energy and need to slow down. Red is “stop” — you are exhausted. Stopping when you are at yellow is more likely to be beneficial. See the tracking sheet on page 6 to learn how to make this work best for you. The goal is to stay out of the red most of time.



Cognitive Fatigue Tracking Sheet

Cognitive fatigue is common. Use this tracking sheet to help you become more familiar with your successful strategies. Then try to regularly incorporate these skills to reduce cognitive symptoms related to overexertion.

Situation: What was going on?	Fatigue symptoms		Strategy to bring you closer to Green	Was this strategy effective? Why or why not?
Example: Out for lunch with friend, then grocery shopping, then home to make dinner.	Drained, feeling low strength. I keep forgetting what step I am on for recipe.	Border red	Sitting for 10 minutes to meditate or doing deep breathing exercises.	Yes. I felt more focused



SECTION THREE: Managing Memory

Many people with brain cancer have memory issues due to the disruption of neural pathways common to brain cancer and related treatments.

This can have a real impact on daily activities and relationships. Memory is a complex process and there are numerous strategies which can help. Rebuilding neural pathways takes time and practice. Having self-compassion and patience with yourself will be crucial as you learn new ways to remember information.

When working to improve your memory, it is helpful to begin with an understanding of your learning preferences and with systems that you may already have in place. Here are some things to consider:

- **Is fatigue the main issue?** Fatigue can interfere with your ability to absorb or recall information. Address fatigue first and know how to recognize when you are too fatigued to learn or remember well. See the section on *Managing Cognitive Fatigue* (pages 4–6) for more information.
- **What is your learning and recall style?** When learning or recalling information, some people like to ‘hear’ it, others like to ‘see’ it, others are hands on and like to ‘feel it’. Think about the last time you remembered something easily. Was it easier if you saw the image as a picture or if you heard it being said? Knowing your strengths and learning patterns can be helpful when developing your plan to strengthen your memory.
- **What memory strategies do you already use?** Think about the strategies and systems you already rely on to remind you (examples: calendars, designated places for items, email reminders, to-do lists, etc.). Starting with what is already known can make the process less overwhelming.
- **What works for you?** You may notice certain times and situations that make it harder or easier to remember information. Try using these situations as opportunities to help you learn what works for you. Consider getting input from your loved ones too. Use a tracking system to help you, such as the *Memory Strategy Tracking Sheet* on page 9.

MANAGING MEMORY

Here are some specific strategies that others have found helpful for remembering information. You might pick and choose where to start. It is not necessary to attempt all of these at once or in any particular order.

Make it Personal

- **Associate new with known information.** This is a great technique for remembering people's names. The sillier the better! For example, if you meet someone named Alice and you might try to picture her wearing a dress like the one worn by Alice in Wonderland.
- **Create an emotional connection.** Link your new information to a personal feeling to recall it better. Strong emotional connection to the information can help you to remember it better.
- **Do something creative.** You are more likely to remember things that are novel. For example, when you park your car, sing a fun song or do a little dance that incorporates key landmarks to make it stick in your mind. Have fun with it!

Make it Clear

- **Learn when most alert.** Plan your important meetings during times when you are most cognitively fresh.
- **Use reminders.** Watches, phone alarms, timers and electronic calendar reminders can notify you of important tasks at specific times (medications, appointments, etc.). Consider placing sticky notes in places that will be noticed when you need a reminder. For example, a note on the car steering wheel can remind you to pick up groceries on the way home from work.
- **Minimize distractions.** Create an environment that supports learning. Turn off non-essential electronic notifications. Declutter your visual environment. Try to do just one thing at a time.
- **Rehearse.** Repeat the new information several times. This can be done verbally (say it aloud to yourself) or mentally (taking a few moments to take a mental snapshot).
- **Ask questions.** It's OK to ask others to repeat information, say it in a different way or get clarification on what was said.
- **Use multi-sensory techniques to aid learning.** For example, when learning a new task, in addition to listening to verbal instruction, you can say it aloud, write it down, visualize yourself doing it, or practice doing it. If helpful, ask others to offer important information in more than one format.



Make it Organized

- **Have one calendar and review frequently.** Be consistent about keeping time-sensitive information in one place, such as a daily planner. Get into a habit of checking the planner daily at set times. Reviewing notes while reading them in your head or out loud will help the memory storage process.
- **Group things together.** Associating things that naturally go together can make them easier to remember- for example, taking your medications with meals. Also try mnemonics such as rhymes or acronyms to make remembering information easier.
- **Have a central notice board** to help remind loved ones of joint tasks– this can be useful to reduce confusion and missed information. Remind others to look at it frequently.
- **Use an organized and categorized system.** Consider labels on drawers and using categories to file information so you know where to look for each. Try to use similar categories across paper and electronic platforms. Caregivers and/or organization professionals can help.
- **Create an assigned place for items.** Have an assigned place for items and consistently putting items back can be helpful, i.e. basket for keys by the door, medications in bathroom drawer, etc.

Memory Strategy Tracking Sheet

Memory slip ups are common. Use this to problem-solve new organizational strategies and track what works.

What was going on when I forgot something?	What didn't work?	The strategy I will use to improve my memory for this information...	Was this strategy successful? What should I change?
Example: When I am leaving the house, I forget where my keys are.	I don't have a designated place for my keys. I do have one for wallet, which has been helpful.	Have a designated place for keys. I can keep them with my wallet.	I got out of the house sooner, because my keys and wallet were easily found in their designated place.

SECTION FOUR: Managing Executive Functioning

Surgery or cancer treatment to the brain can result in changes to executive functioning. These are the skills that help you plan, organize, and get activities done.

Executive functioning also helps you stay on track, monitor progress, and keep within a timeframe. If you have difficulties in these areas, then you may consider adding more structure to your daily routine to help you be more successful. Also, consider these strategies.

- **Be consistent with an organizational system that works for you.** A good organizational system that is used consistently can help keep you on track and keep you from making mistakes. Keep it as simple as possible. When things don't work out, use it as an opportunity to learn what else might be needed. Be gentle with yourself as you try out, practice, and re-learn these skills. Consider approaching it like you are finding a 'new normal' rather than getting back to exactly where you were.
- **Have a schedule to tackle your day.** A daily plan will increase your chances of getting tasks done. At the beginning of your day, write down a To-Do list prioritized by urgency of needing to get done. Include specific times and how much time you think it will take to get it done. Make it manageable and stick to 3 to 4 tasks per day – you can always add more – but be sure to prioritize what is most important.



- **Create step-by-step checklists.** Break down a big task into smaller, more manageable tasks (especially important if you find yourself frequently overwhelmed). For example, if the task is to apply for a job, break it down to sub-tasks, such as:
 1. Look in computer files and locate previous resumé.
 2. Update resumé with latest job/school/certificates.
 3. Ask a friend to help with editing and formatting resumé.
 4. Search job openings on LinkedIn and Indeed.
 5. Submit resumé online.
- **Use an alarm or timer.** Get in the habit of doing tasks in 20- to 30-minute chunks with rest breaks in between. Set an alarm or timer to go off telling you when to start and stop. You can use apps such as Pomodoro, your phone alarm, a device such as Echo, or even a simple kitchen timer. Also use alarms to keep from sleeping in late or from napping too long.
- **Consider asking others to offer feedback and prompts.** Friends or family can be a source of support to you too. Let them know when something is important to you and give them permission to prompt you periodically.
- **Stick with it.** Adhering to a calendar and to-do list may seem daunting at first if you're not used to it, but over time it can lower your stress, increase your confidence, and enable you to live life with a sense of freedom knowing that your responsibilities are managed.
- **Notice and acknowledge your efforts.** Sometimes we move from task to task without taking time to simply acknowledge and notice what we are doing and all we have done. Tracking your successes and applying them to your future efforts can be helpful. When you complete a difficult task, take a few minutes to feel proud of yourself for the effort involved. Your brain is working harder than ever before!
- **Still struggling despite your best efforts?** Talk to your doctor to see if a specialist such as a neuropsychologist (<http://tiny.ucsf.edu/care>), speech language pathologist, and/or occupational therapist might help.



SECTION FIVE: Managing Attention and Concentration

After brain cancer and related treatments, many people find they have more difficulty focusing on the task at hand.





Some of this may resolve on its own over time as the brain re-adjusts after treatment. Yet some of it may be the 'new normal' going forward. Consider trying these strategies to help manage and improve your attention and concentration.

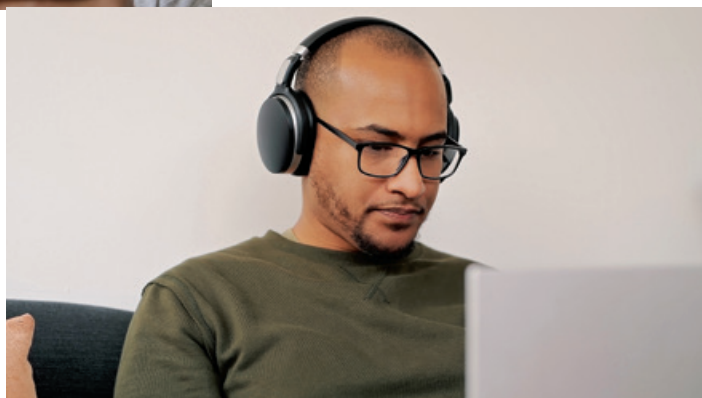
- **Attend to cognitive fatigue first.** You will be able to concentrate much better when you are not fatigued. If you don't have time for a full nap, try a 'brain break' of closing your eyes and shutting off sounds for a few minutes.
- **Manage distraction.** Unnecessary sensory input can pull your attention away to something else before you have a chance to complete what you were doing. Reduce potential distractions by turning off TV/radio/email notifications, pulling down blinds/curtains, repositioning your work desk, closing down unneeded computer programs, using 'focus' features on devices, blocking internet pop-up messages, etc.
- **Do one thing at a time and switch between tasks more slowly.** Many people find that they are more effective at doing one thing at a time rather than multitasking. Also, consider building in more time to transition between tasks.
- **Notice instances when concentration is most difficult and/or especially focused.** If you are aware of the circumstances around when your concentration is either strong or vulnerable, you can use this information to build a strategy to fill the gap. Consider getting input from loved ones to find creative solutions.
- **Talk through steps aloud as you do them.** Talking aloud through the steps of a task while you do them helps to keep you on track and focused (i.e., "I'm going upstairs to find my glasses; I'm looking for my glasses" etc.).
- For complex tasks requiring multiple steps, **break down into smaller steps**, write them out, then check off once completed.

- **Use a ‘focusing’ phrase.** If you feel you are losing concentration have a phrase (i.e., “stay on track”) to return your attention to the task at hand.
- **Sometimes stress/anxiety/worry/depression can get in the way.** You can lessen the impact by using STOP-FOCUS-RETURN: Notice as soon as you can when you are distracted (STOP), put your full attention on your breath (FOCUS) to clear your mind, and then return to your intended task (RETURN). Also, consider stress buster strategies such as journaling, talking to someone for support and/or problem-solving, and simply setting aside a specific time to think about what is on your mind. When you are feeling especially anxious, try the 5-4-3-2-1 grounding technique (at right). If feelings of anxiety or depression continue, talk to your doctor about a referral to a psychologist or psychiatrist.

5–4–3–2–1 Grounding Technique

If you are experiencing panic or anxiety, you most likely are consumed by a future worry. This simple technique helps anchor you back into the present moment so you can concentrate:

	Name 5 things you can see around you
	Name 4 things you can feel on your body
	Name 3 things you can hear right now
	Name 2 things you can smell
	Name 1 thing you taste



SECTION SIX: Managing Sleep

Difficulties with sleep are common to individuals with brain cancer, yet there are strategies that can help. We can't force ourselves to fall asleep, but we can establish a routine and environment that makes bedtime sleep more likely.

By committing to a regular bedtime ritual that includes sensory relaxation, your body will eventually start to respond automatically and help you get a good night's sleep. Here are some proven strategies that may help to improve the quality of your sleep.

- **Establish a bedtime routine.** A bedtime routine begins to signal to the brain that it is time to sleep. Consistently engage in winding-down activities that are pleasant and non-activating such as a bath, reading or listening to music. Limit work and triggering activities (i.e., agitating news programs, family arguments, paying bills) one hour before bedtime.

An example of a bedtime routine might look like this:

8:30 pm: turn off all devices

9:00 pm: warm bath with lavender oil

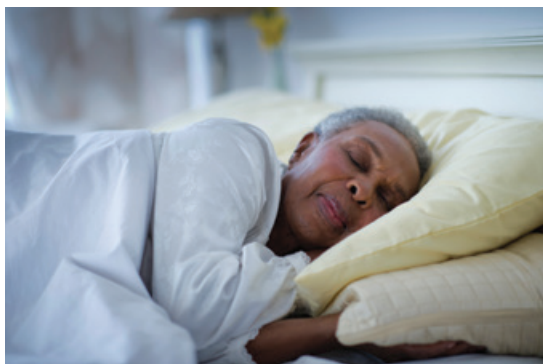
9:45 pm: wash face and brush teeth

10:00 pm: relaxation practice (meditation/stretching)


10:30 pm: lights out

- **Mimic natural light levels and minimize screen exposure during winding down.** Be sure to get exposure to natural light during the day. This will help set your body's sleep-wake cycle, known as the 'circadian rhythm'. Start dimming the lights an hour or so before bedtime and keep artificial light to a minimum in the bedroom. You can put tape over the LED lights on monitors and power strips. Blue light transmitted from screens can disrupt sleep signals in the brain. It is best to limit their use one to two hours before bedtime.

- **Regulate caffeine and alcohol.** Keep caffeinated beverages to a minimum, especially in the afternoon and evening. Be mindful that alcohol can interfere with sleep quality.
- **Make your bedroom conducive to sleep.** Create an environment that is dark, quiet and cool. Consider fans, eye masks, ear plugs and/or white noise machines. You may also consider light-blocking drapes if outside light is an issue.
- **Limit lying in bed awake.** If you wake up in the night, don't let yourself lie awake in bed longer than 20 minutes. Consider creating a 'nest' area or alternative place where you can go and sit until you feel drowsy enough to go back to bed to sleep. This helps the brain to associate the bed with sleeping only.
- **Reserve your bed for the 3 S's:** Sleep, sex and sickness. The brain is constantly making associations of how to regulate or respond more quickly in various environments. Activating activities like working or watching TV is best reserved for other areas of your home. Help your brain associate your bed with sleep.
- **Discuss your bedtime ritual with your housemates and bed partners.** Working together can help you reduce conflict that can interfere with getting good sleep. For example, if your partner likes to watch TV in bed, you may need to brainstorm to come up with other compatible alternatives (i.e., they watch TV in another room or use headphones).
- **Find ways to manage anxiety at bedtime.** If you find yourself worrying a lot when you try to fall asleep, you might want to consider actually scheduling some time during the day to address these concerns. This may help reduce the random worries that pop up as you are trying to fall asleep. If they do pop up at night consider keeping a pen/paper by your bed to write down "To Do's," ideas or anxious thoughts to help you cope or let go so you can relax and fall asleep.
- **Consider a pleasant mental activity right before sleep** such as meditation, recalling three things that delighted you or you feel most proud of from the day, or listing some things in your life that you feel grateful for. Similarly, avoid emotionally triggering experiences and conversations before bed.
- **Try earlier or shorter naps.** If you currently nap during the day, you might want to experiment for a few days napping earlier in the day or for shorter periods and see if it makes any difference to your night-time sleep quality. The goal is to help you with better quality sleep, not necessarily quantity, and naps may or may not interfere with this.
- **The exercise prescription.** Daytime physical activity that is moderate to high intensity is beneficial to nighttime sleep quality. However, do not exercise within 2 hours of going to sleep as it will energize you. Focus on relaxing physical activities in the evening such as stretching.
- **When in doubt, talk with your doctor.** Work with your doctor to determine whether any other underlying medical conditions such as sleep apnea might be interfering with your sleep. You may want to discuss other options such as melatonin supplements with your doctor.



SECTION SEVEN: Managing Social Situations



Have relationships in your life become harder since your diagnosis and treatment? Do you struggle with feeling like you aren't sure what to say? Do you feel frustrated that others may misunderstand you? Individuals with brain cancer can often struggle with managing their relationships and navigating social situations.

This is difficult to tackle with general strategies because it can vary so much from person to person and according to the situation. Your openness to learning from your experiences, cultivating compassion, and accepting honest feedback from trusted people can be helpful guiding principles. Here are some suggestions to help:

- **Please be compassionate with yourself and others!**

Your brain has been affected and is adjusting to these changes. And just as you are adjusting to these changes, other people in your life are too. Be patient with yourself and others. If you make a mistake, reflect on what went well and what you want to try differently the next time. What has worked for you in a similar situation in the past? What have you seen others do which might have worked?

- After speaking, ask yourself if this had the intended impact.

Try to **be aware and learn from your listener's reactions** (e.g., facial expressions, body language, verbal cues) to evaluate the effect. You can use the table below track what works and what doesn't.

- If you can identify when social slip-ups happen most often you can track, problem-solve and **plan ahead** for certain situations. If you tend to be more apt to make mistakes when you are tired, consider resting prior to putting yourself in social situations. Take breaks when necessary.

- **Rehearse and role play** prior to going into a social situation. Practice saying your main points and introducing topics you will talk about. If you have someone you can role play with, even better!

- **Ask for what you need from others.** For example, ask clarifying questions and request that others repeat what they said. If you get lost in a conversation, just find a place to jump back in when you are ready.

- It is common to speak without thinking it through. Consider a **“Catch It – Check It – Change It”** strategy (three C’s). The three C’s can help you to **slow down and get your point across more clearly**. *Catch* yourself before you say something that may lead to problems and take a breath before responding. *Check it* – consider if it is a ‘think it’ versus ‘say it’ statement (see below). Is it helpful to the current conversation? If not, then *Change* it.

Think It	OR	Say It
Personal information about someone		Relevant information about yourself
Sarcasm, insults or negative comments about someone		Helpful, positive or respectful comments
Comments about physical appearance or race		Personal opinions that are respectfully presented.
Facts that are off topic (unless you preface it with “I know this is off topic but...”)		Facts that are on-topic. If you get lost in the conversation, then request to have speaker repeat or say more in order to help you get back on track
Questions that are overly personal or that may make the person feel uncomfortable		Questions that stem from respect and curiosity, but are not too personal

Other ideas:

- **Consider help** from a family member, close friend or work colleague – someone you trust – to give you honest feedback and to help you see instances of “thinking versus saying”. You can ask clarifying questions if you don’t quite understand.
- Ask trusted others to **give you a signal or sign** when you are perhaps talking too much or straying off the topic. This will increase your real-time awareness of how you are interacting and communicating with others.
- There are **professionals** available to help. Talk with your neuro-oncologist about seeking a referral to someone who can help.



Social Situation Tracking Sheet

Use this to identify and problem solve for social slip-ups that are especially troublesome or happen most often. Track what works so that you can incorporate new skills and feel more confident in social situations.

What was going on when the challenging moment occurred (situation, thoughts, feelings, behaviors)?	What were the consequences?	What is in my control that I can use early on to Catch it, Check it and Change it?	Was this strategy successful? What should I change?
Example: I was having a conversation, and the other person became upset when I shared my personal information	The other person became upset because I over-disclosed. It caused friction in my relationship	Try pre-planning. Before going to lunch think about some safe topics. Have some short responses ready for sensitive topics, or simply change the subject. Use the three C's. Is it a 'think it' or 'say it'?	Yes. Pleasant conversation. Next time I will also include questions to ask to keep the conversation flowing.

Conclusion

We hope that you found the cognitive education in this booklet helpful. Working toward effectively managing your cognitive changes can be challenging and yet incredibly rewarding.

Also, we hope cultivating grace and self-compassion can buffer the stress of learning new strategies. As you encounter new challenges, you may find it helpful to come back to these strategies with fresh eyes and see new ideas. Finally, please remember that there are professionals and peer volunteers to support you through this, too.

UCSF adult brain tumor patients are encouraged to seek support through our UCSF Neurocognitive Services. Ask your UCSF neuro-oncologist for a referral.

For additional support on Living Well with Brain Cancer, visit:

- The Sheri Sobrato Brain Cancer Survivorship Program at <http://tiny.ucsf.edu/survivorship>
- The Gordon Murray Caregiver Program at <http://tiny.ucsf.edu/GMurray>
- The Jeanne Capurro Marin Expansion Program at <http://tiny.ucsf.edu/MarinSupport>



Words from Survivors

“ There is a big difference between feeling *humiliated* and feeling *humbled* by this disease. Cognitive changes are a normal part of brain cancer. Yet with the support of others and by using these strategies, we can adapt and adjust — and maybe even gain self-acceptance — along the way. ”

– L. Daniels, 11-year survivor

“ It’s been helpful for me to realize that it is ok if my best today isn’t the same as my best yesterday. The best I can do *right now* is the most I can ever ask of myself. It’s also helpful to remember that we can control little about life except for how we react. And even when we get that wrong, we can always try again. ”

– Dace, 7-year survivor

“ At first I believed the only way to survive a brain tumor diagnosis was to go through it alone. The UCSF Brain Tumor Survivorship Program showed me how I could survive better, even thrive, with the support of others. ”

– Katie, 2-year survivor

“ My healing began with self-love, self-care, and acceptance of my brain condition and treatments. I have learned to combat brain fatigue and I have also started exercising, meditating and staying mindful of my feelings. I may not be the same as I was before but I am still uniquely designed. I am a Brain Cancer Survivor! ”

– A.L., 3-year survivor

“ Don’t worry about rushing it. I found that taking it slow and easy was the way to go. Just focus on your next step and trust that you will progress. For me, it took a while to regain my skills. I didn’t even know I was rebuilding, until one day I looked back and realized how much I’d changed. ”

– Kelly, 4-year survivor



Our mission is to enhance the wellness and quality of life of patients with brain tumors through a collaborative, multidimensional approach focusing on emotional, physical and cognitive health.



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