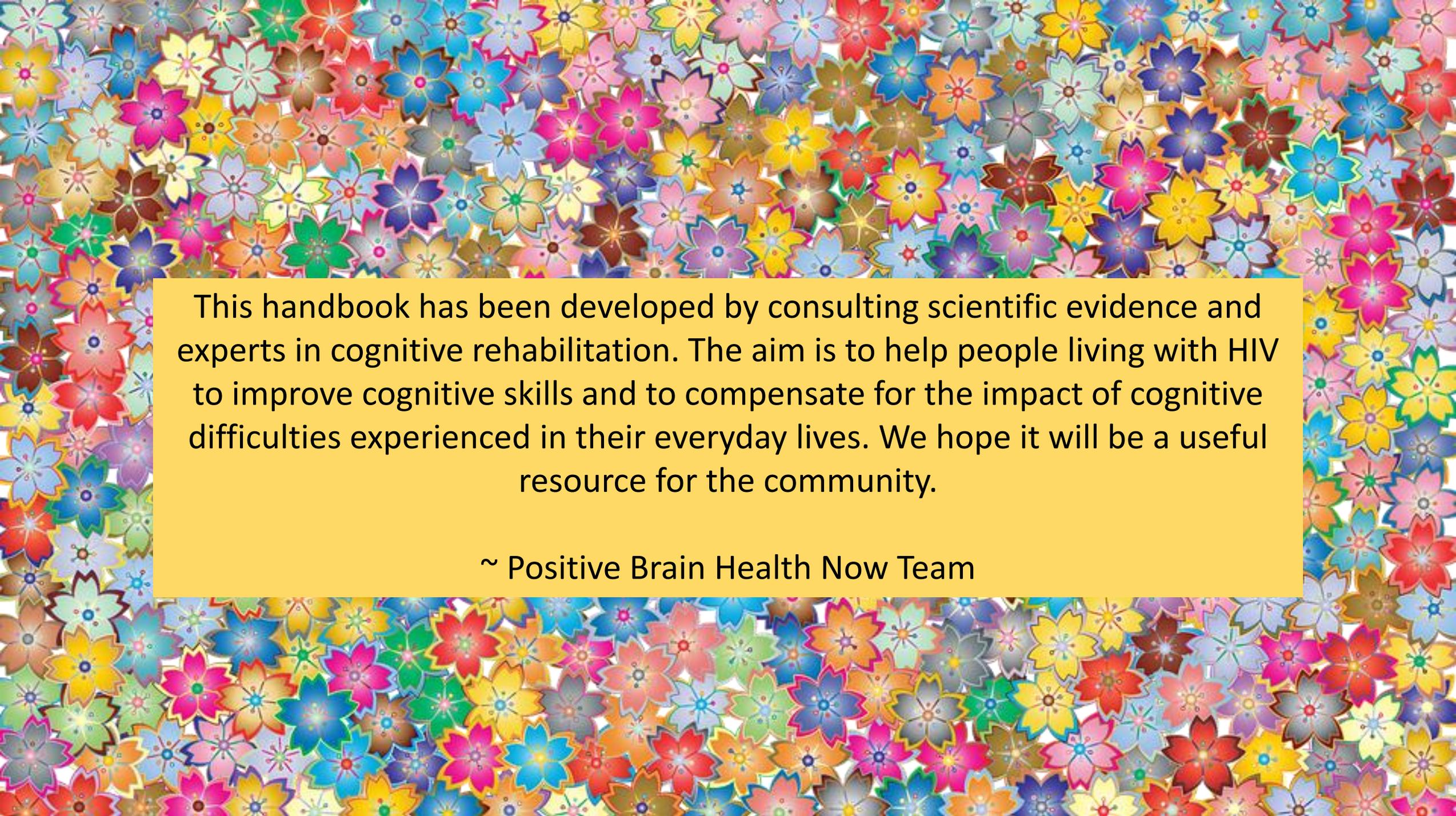




Self-Management of Cognitive Difficulties

A Handbook for People with HIV



This handbook has been developed by consulting scientific evidence and experts in cognitive rehabilitation. The aim is to help people living with HIV to improve cognitive skills and to compensate for the impact of cognitive difficulties experienced in their everyday lives. We hope it will be a useful resource for the community.

~ Positive Brain Health Now Team

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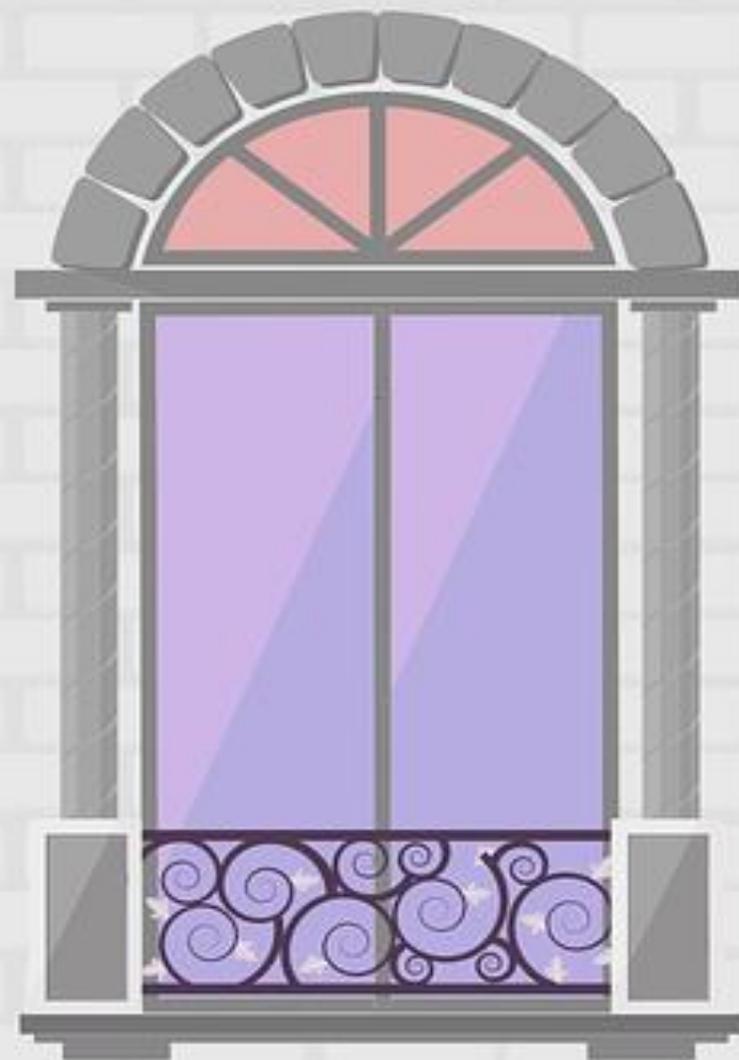


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HIV can affect the human brain – some people living with HIV find it difficult to concentrate, to remember things, and to plan and organize complex tasks. These difficulties can interfere with everyday activities and so it is important to manage their impact. We will provide some helpful strategies in the following pages.





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Assess Yourself



1. Please complete the form on the next page.
2. Circle how often you face a specific cognitive difficulty/concern.
3. Add the scores.
4. Then have someone else assess you.

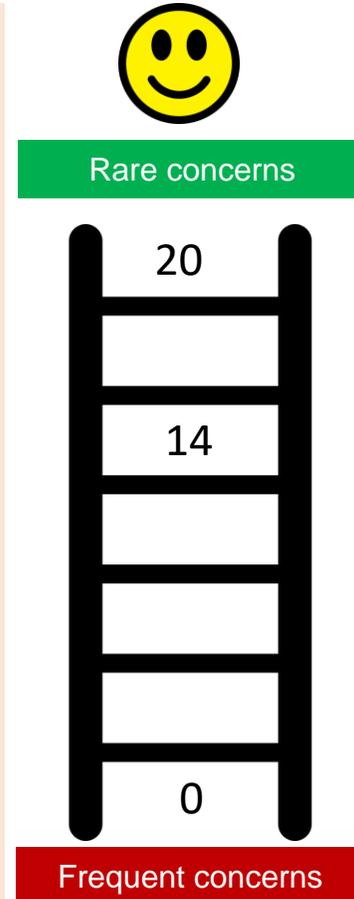
The best possible score that you can achieve is 20. This would mean that you have hardly any trouble with your memory, thinking and planning skills. A score of 0 indicates you have frequent trouble with these skills.

How Often Do You Forget Or Lose Focus?

Concern	Frequently (almost every day)	Sometimes (once a week)	Rarely (once a month or less)
MEMORY			
1. I forget what I was about to do.	0	1	2
2. I forget tasks or activities I need to do.	0	1	2
3. I forget what I have just read.	0	1	2
4. I forget when doing complex tasks.	0	1	2
5. I forget if I had already done something.	0	1	2
6. I forget I have food cooking.	0	1	2
ATTENTION & CONCENTRATION			
7. I lose focus when I have to pay attention to two things at a time.	0	1	2
8. I lose focus and I end up with too many thoughts in my head.	0	1	2
9. I lose focus on a conversation	0	1	2
PLANNING & ORGANIZATION			
10. I can't be organized.	0	1	2
Total Score (Best = 20)			

How Do You Measure Up?

- The form that you just completed is called the Communicating Cognitive Concerns Questionnaire [C3Q].
- Check if your self-assessment differs from how your friend/family member assessed you.
- Discuss the areas where you find any differences.
- Monitor these areas and talk to your doctor if need be.



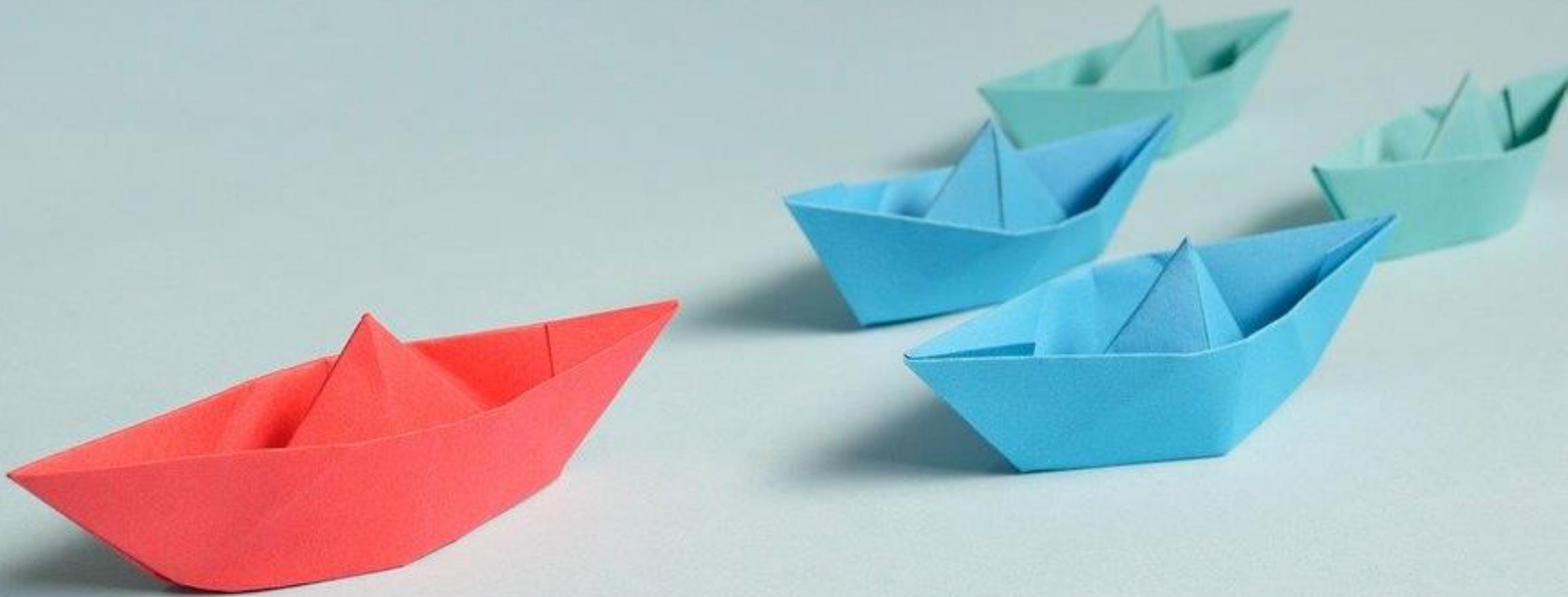
- It is normal to forget things or lack concentration from time to time.
- A survey of older Canadians noted that the average score on the questionnaire you just completed was 14.
- This handbook has some strategies to improve your place on the ladder.



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Now that you have assessed yourself, it is important to understand the process how memories are formed. Knowing the process will help you in finding ways to improve your memory. This will be useful no matter how you did in the assessment.

The Making of Memories

Register

Store

Retrieve

A piece of information is received through the five senses; by paying attention, the brain converts this information into a form that can be stored. It is held first in short-term memory. The information that is ignored quickly fades!

The brain transfers some of the information from short-term memory into the storage of long-term memory.

This can be helped by repeating the information over and over again in the mind.

Getting it back “out” – You can recall the information stored in your long-term memory when needed.

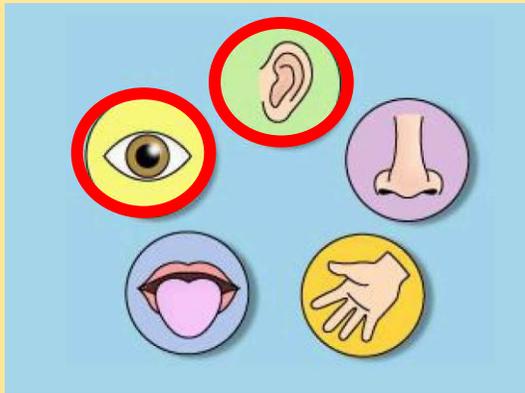
Memory Making: An Example



Any piece of information, e.g., lyrics of a song



Attention



Received through specific sensory organs



Short-term storage

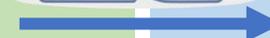
Forgotten without repetition ("Leaky bucket")



Repetition



Long-term storage



Retrieve

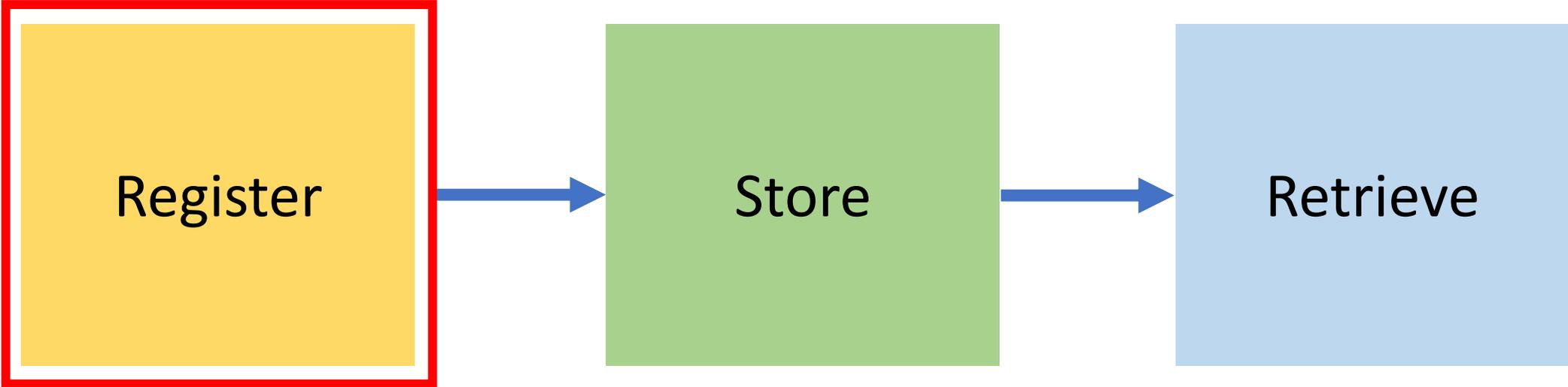
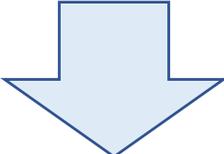


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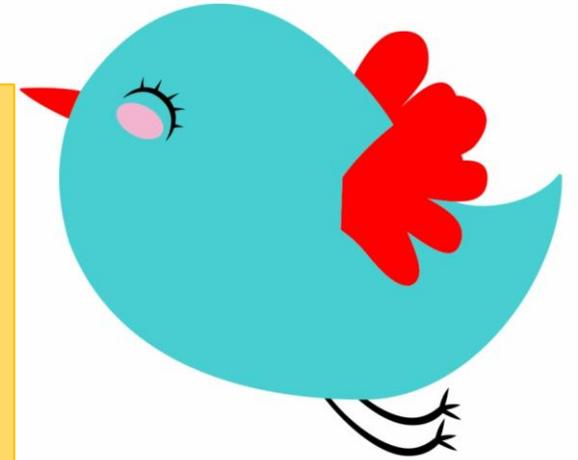
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Strategies for Improving Attention and Concentration



- Concentrate on one thing at a time.
- Try to carry out important or complex tasks in a quiet area.
- Ask yourself what may distract you, for example, phone notifications, bright light or excess noise from TV, radio, dishwasher when you know you need to concentrate. Try to remove those distractions.
- While talking to someone, try repeating things that they say in your own words. This may help you to follow the conversation and feel confident that you have grasped it.
- Avoid socializing in crowded and loud environments.
- For a complex task, break it up into steps. Verbalize, write down or visualize each step before you do it and check off the steps as they are completed.





Try not to multitask. It interferes with the formation of memory by decreasing attention.

Focus on one thing at a time.

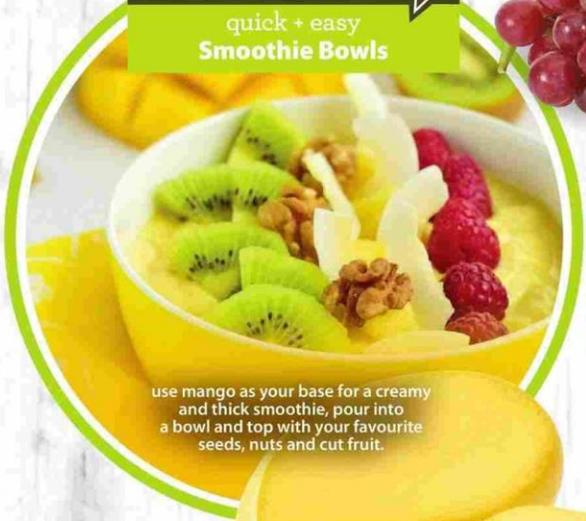


Challenge your mind in your everyday life. For example, try naming ten things that you notice after walking down a block.

ENJOY THE VERY BEST QUALITY & VARIETY AT AMAZING PRICES

fresh solutions

quick + easy
Smoothie Bowls



use mango as your base for a creamy and thick smoothie, pour into a bowl and top with your favourite seeds, nuts and cut fruit.



Red Grapes
Seedless,
No.1, Chile,
6.59/kg
2⁹⁹
lb
sale



Cantaloupe
No. 1 Grade,
Imported,
2.18/kg
.99
lb
sale



Navel Oranges
Booth Ranches –
USA, Extra Large,
2.84/kg
1²⁹
lb
sale

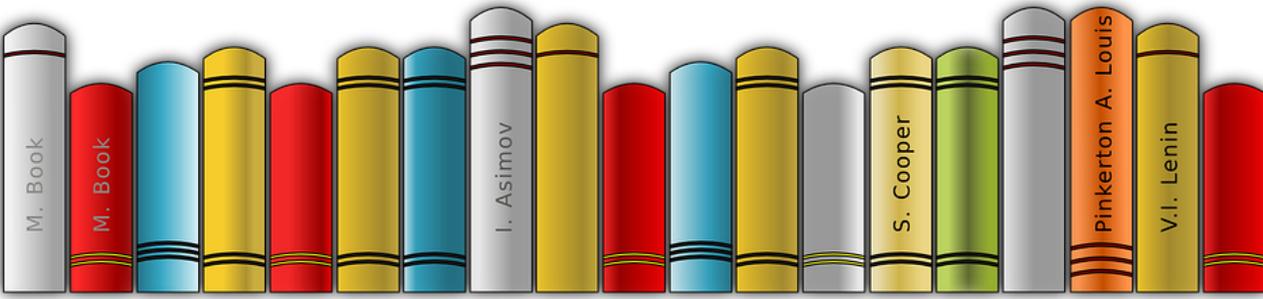


Raspberries
Mexico,
1 Pint
5⁹⁹
ea
sale



Ataulfo Mango
Mexico, Approx.
2.27 kg Case
7⁹⁹
ea
sale

You can look at the grocery flyers and name 10 items that are on sale.

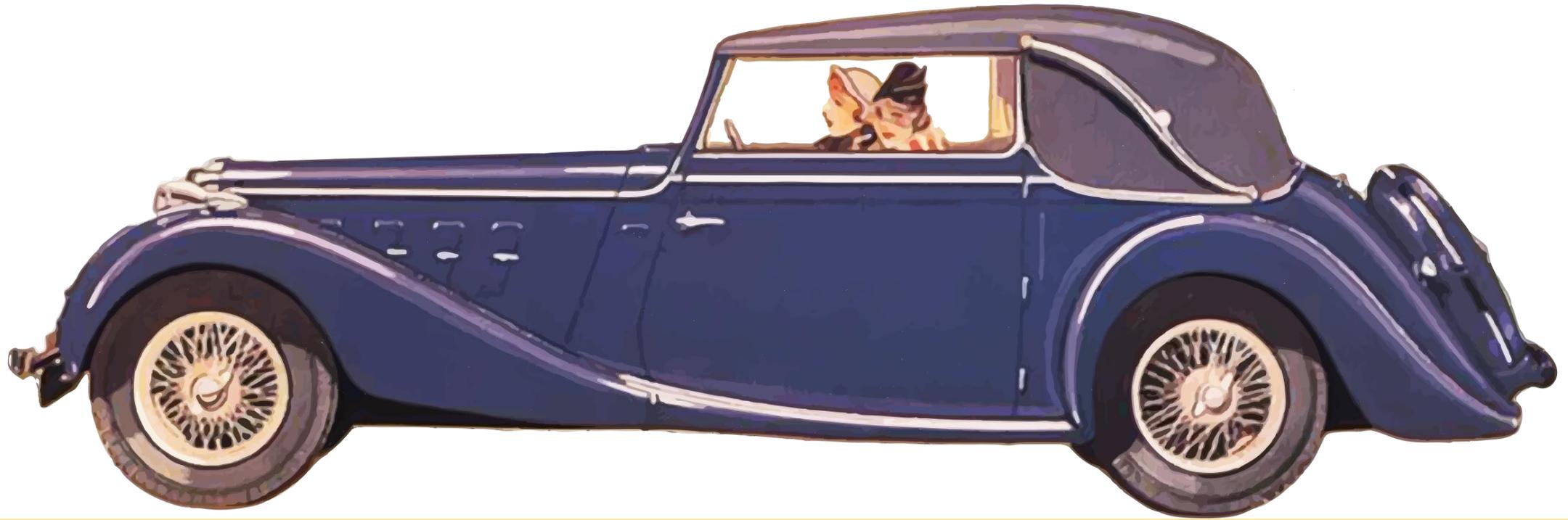


If you have problems remembering what you have just read:

- Read the text aloud.
- Try rephrasing it in your own words.
- Pretend that you are trying to explain it to someone else.
- If reading for pleasure, make sure it's something that really interests you.

Describe a person in detail that you have just met or passed on the street. You can do this activity with a friend/partner to make it fun.





Or describe a car that you passed on the street. Try memorizing its license number and see what strategies you used to remember it.



Pay attention while travelling on public transport. Ask/remind yourself three things:

1. Where am I going?
2. Where do I get off?
3. Why am I going there?

You can ask the same questions to yourself before you leave your house or start driving a vehicle to get to your destination:

Where am I going?
What is my route?
(Visualize the route).
Why am I going there?





Before you enter a building/supermarket, pay attention to the position of your parked car in relation to the exit or the entrance of the parking lot or the parking meter. Note any landmarks that you can easily remember or take a picture of the area with your smartphone where you parked your car.

When walking to the supermarket, rehearse/picture the route in your mind before you set off.



When you meet someone for the first time:

- Listen to their name carefully.
- Pay attention!
- Ask them how their name is spelled.

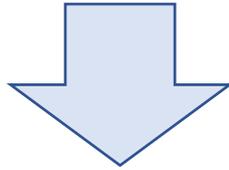


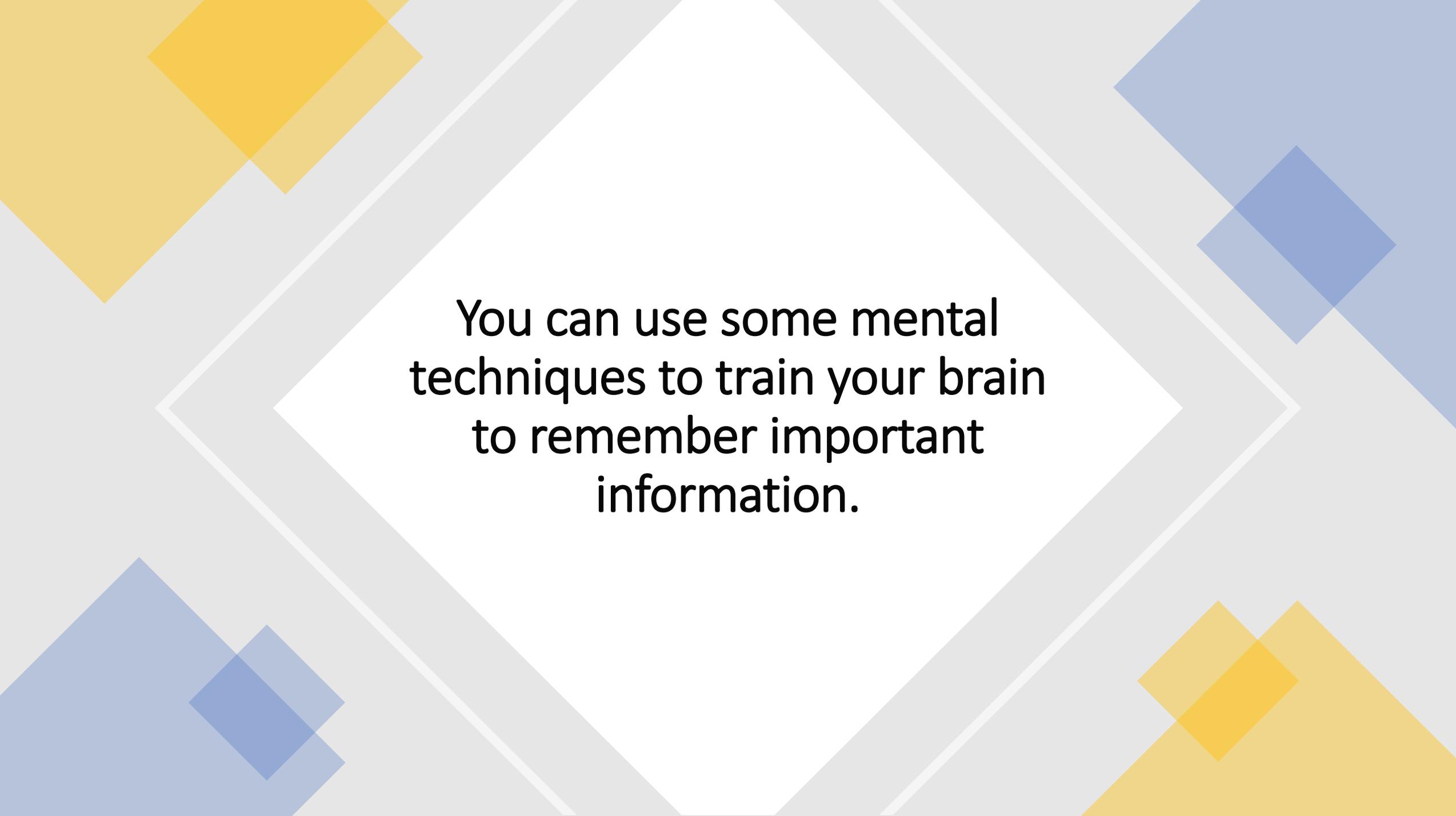
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Strategies for Improving Memory





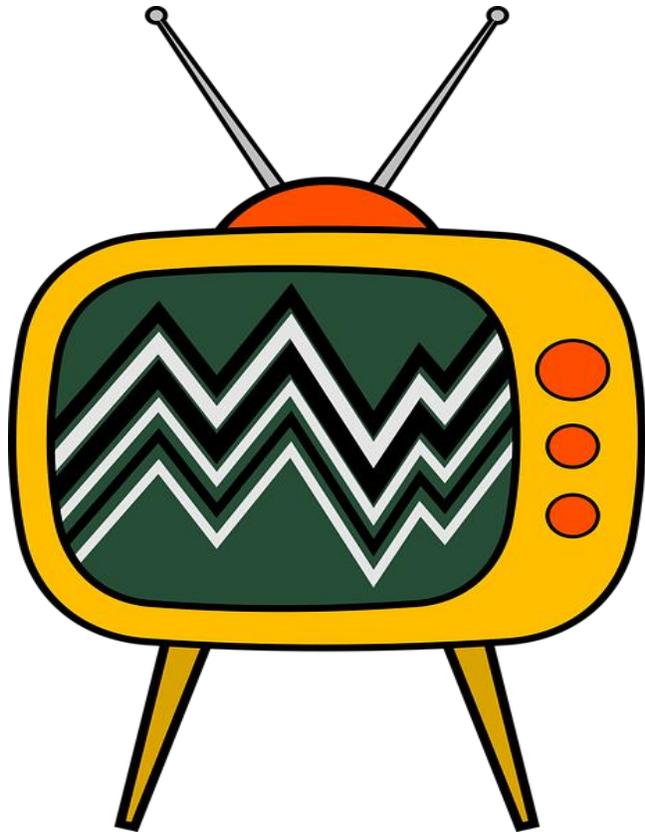
You can use some mental techniques to train your brain to remember important information.

Make Associations!

Use tricks that make information memorable.

To be able to recall a piece of information later, try to associate it with people, places, situations, or feelings that you are already familiar with.

This association doesn't need to be logical. Anything silly, humorous or vivid works great!



For example, remember taking your night pills by linking it up with your favourite TV show or evening news program

Associate the name that you want to memorize with a vivid feature of the person.

- *For example, Carley has curly hair.*

[Novel, bizarre or humorous features get lodged well in memory.]



Have a conversation with the new person.

- Use their name frequently when talking.
- Ask them about themselves.
- Ask for the meaning of their name if it is an unfamiliar name.

[It is easier to remember names in a context.]

Spell the Names!

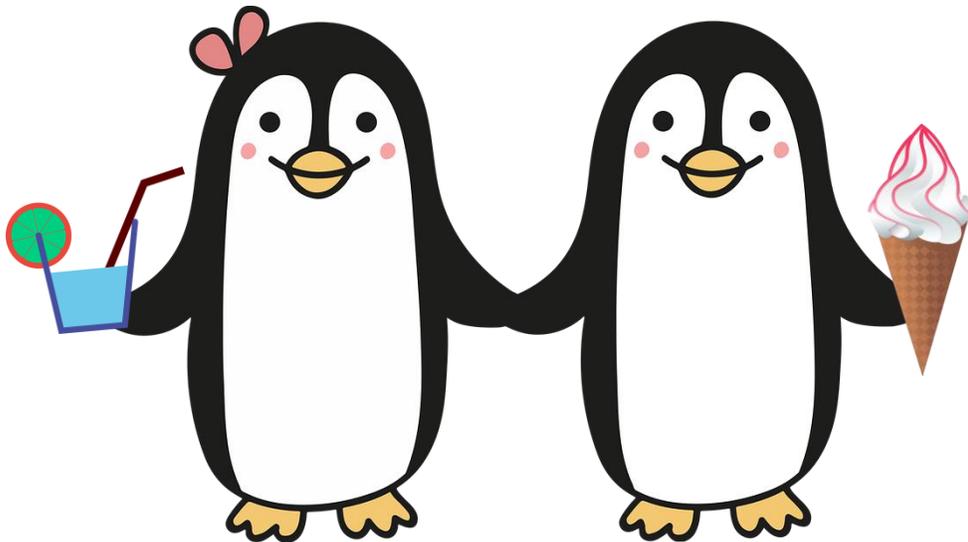
“Hello, my name is Jo-Ann Mitchell.”

“Hi Joanne, nice to meet you! How do you spell your name, Joanne with an E?”

“No, no, with a hyphen and no E, J O - A N N.”

“And Mitchell, 2 Ls or 1?”

“Yes, Mitchell with two LLs, M I T C H E L L .”



Imagining information into interesting pictures can help you remember things better. For example, if your partner asks you to meet them outside the bakery at 5:20 pm after work, you could create a mental image of them standing outside the bakery with a monkey holding a banner saying “5:20pm”!



Picture It!

Chunk It!



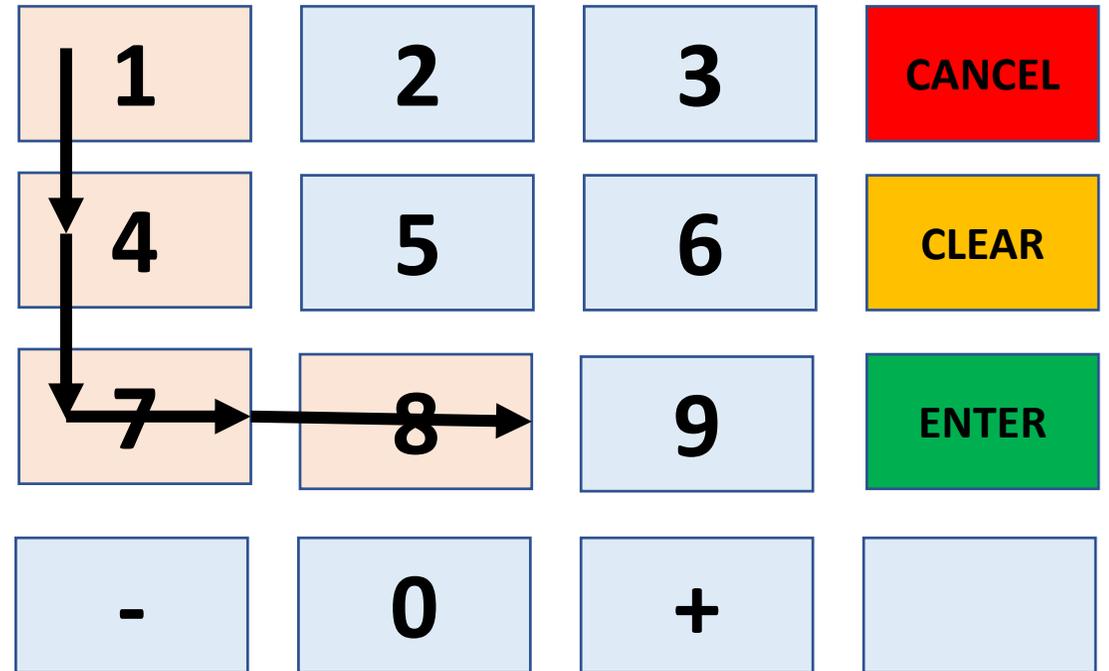
SOCIAL INSURANCE NUMBER

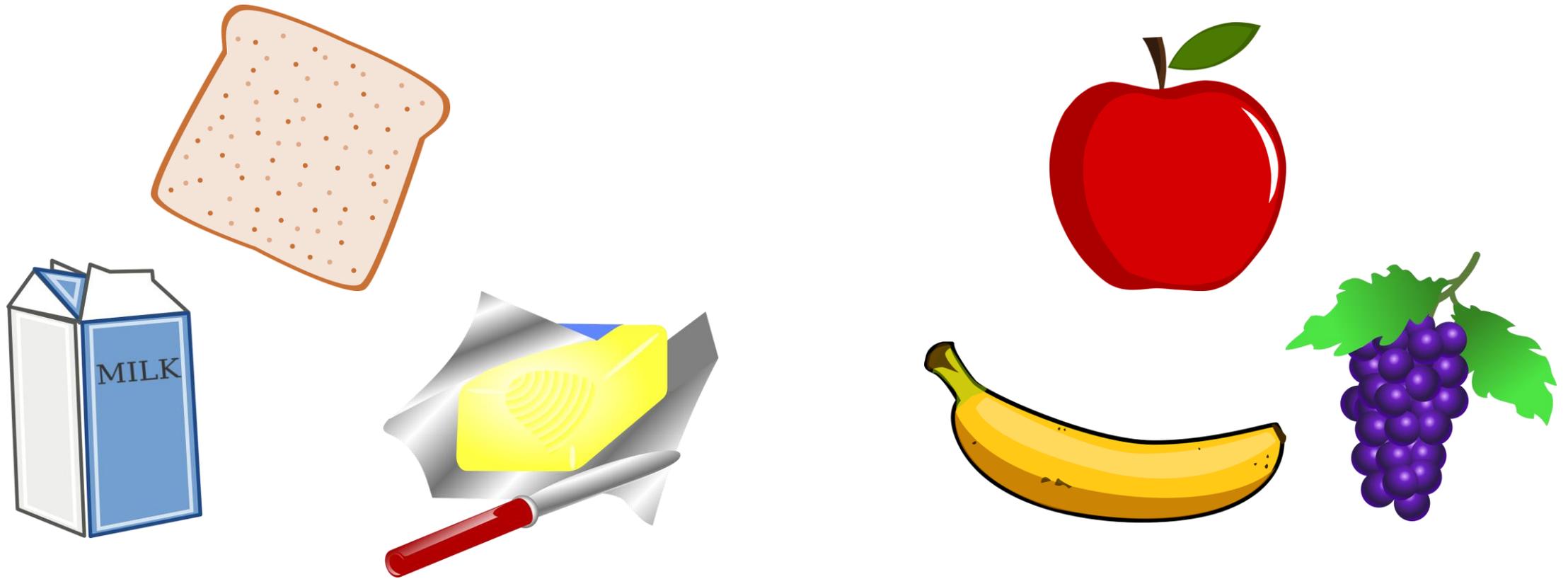
586 699 210

FIRST NAME LAST NAME

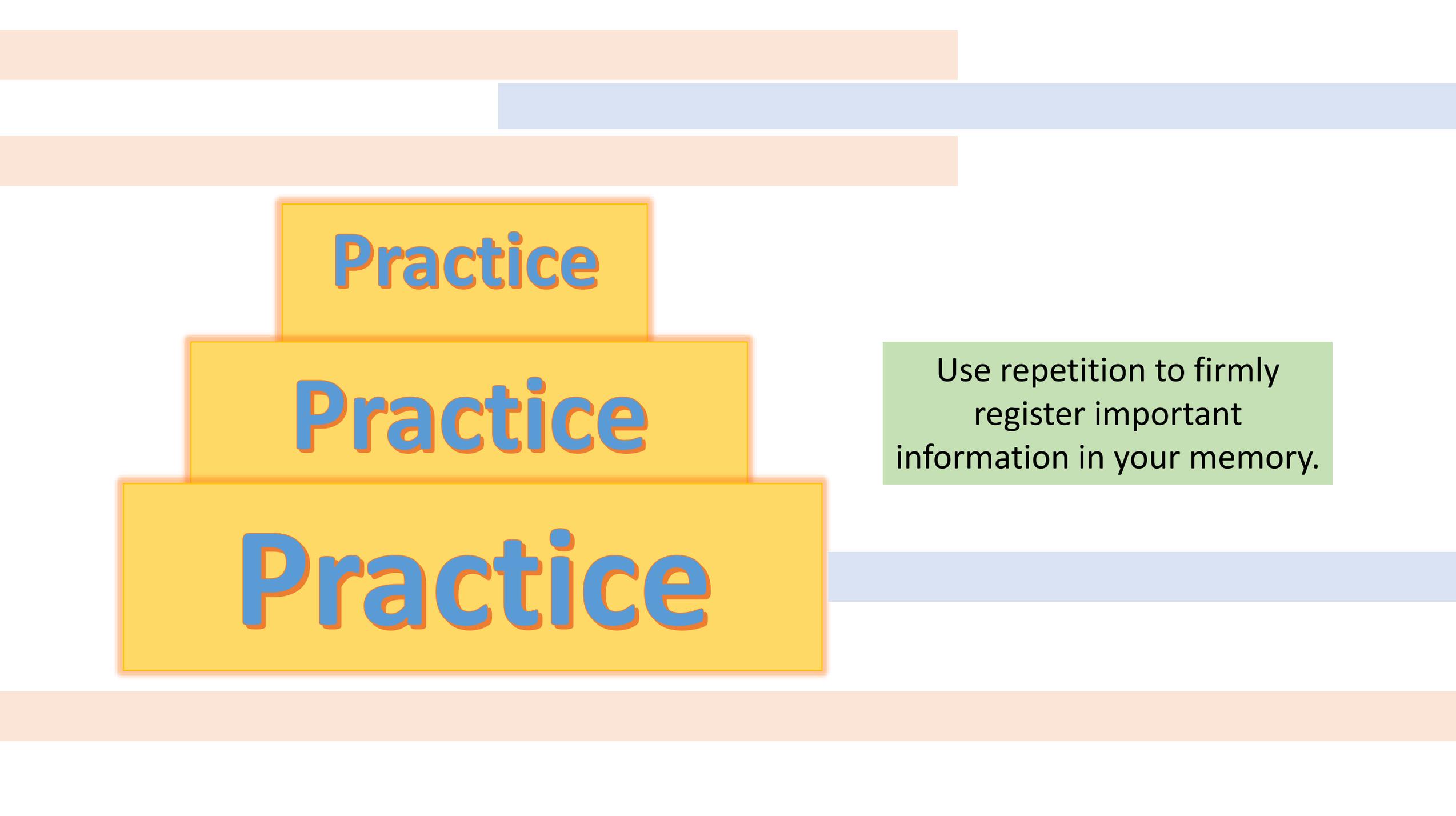
Try breaking down the long numbers in “pairs of three”. You can break down your social insurance number into three smaller chunks (586, 699, 210) that can be easy to remember. Same technique can be applied to bank card numbers, phone numbers, passcodes and lock combinations, etc.

If you were to remember a PIN or your apartment access code, try making patterns. Imagine the numbers making a certain shape or a letter on the number pad: 1478. This method is particularly useful for numbers that create obvious patterns (e.g., an “X” or an “L”).





You can also chunk/group items in pairs of 3 to help you remember things that you need from the grocery store. The items can be grouped together based on their similarities or purpose.



Practice

Practice

Practice

Use repetition to firmly register important information in your memory.

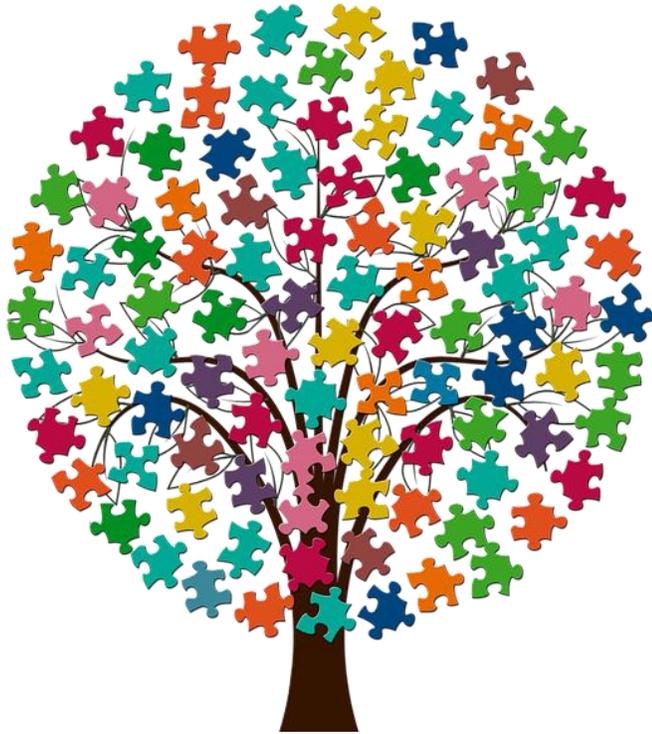
For example, if you met someone at the gym for the first time, you can repeat their name on your way home.



"I met Elvis today."

"I met Elvis today."

"I met Elvis today."



Quiz yourself by *actively* recalling what you need to memorize.

Self-testing more than once after a few minutes/hours/days of learning a piece of information can strengthen the long-term memory.



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Minimizing the Impact of Memory Difficulties



Diaries & calendars

Alarm clocks

Note books

White boards

Lists

Post-its

Smartphone apps

There are several external tools that can help you remember key details or chores. You can pick a tool you like.



In this section, some strategies are given to help you minimize memory difficulties.

These strategies can only be effective if you integrate them in a new routine.

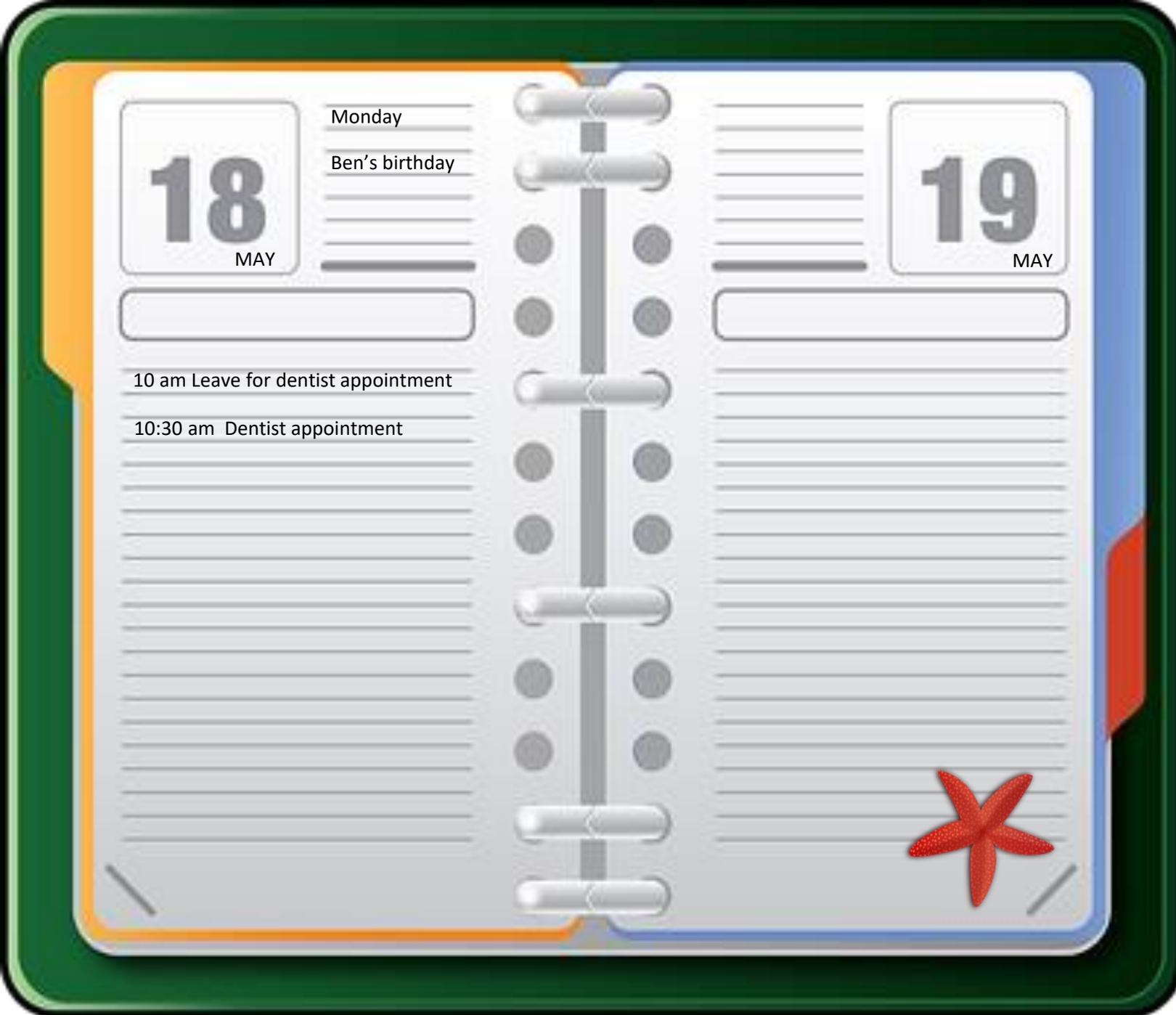
For example, if you plan to use a calendar, get into the habit of writing important chores/appointments on it and check it at specific times of the day!



DECEMBER 2020

SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
				1 1:30 pm: Leave for yoga class 2pm: Yoga class	2 11am: Linda coming for a visit	3 5pm: Leave for the movie theatre 6pm: Watch movie with Mike and Ivy
4 10am: Tim's birthday – call him 11am: Buy groceries 3pm: Clean the house	5 9:30 am: Leave for volunteering 10am: Volunteering	6 7am: Put bins out 1:30 pm: Leave for yoga class 2pm: Yoga class	7 9:30 am: Leave for Spanish class 10am: Spanish class	8 1:30 pm: Leave for yoga class 2pm: Yoga class	9 6:30 pm: Cook dinner for Tim 7:30pm: Dinner with Tim	10 5pm: Watch last episode of The Game of Thrones
11 11am: Buy groceries 3pm: Cleaning	12 9:30 am: Leave for Mindfulness session 10am: Mindfulness at the local club	13 7am: Put bins out 1:30 pm: Leave for yoga class 2pm: Yoga class	14 9:30 am: Leave for painting class 10am: Painting class	15 1:30 pm: Leave for yoga class 2pm: Yoga class	16 6:30 pm: Cook dinner for Tim 7:30pm: Dinner with Tim	17 5pm: Watch the new show on Forensic detectives
18 11am: Buy groceries 3pm: Cleaning	19 9:30 am: Leave for volunteering 10am: Volunteering	20 7am: Put bins out 1:30 pm: Leave for yoga class 2pm: Yoga class	21 1pm: Leave for dentist appointment 2pm: Dentist appointment	22 1:30 pm: Leave for yoga class 2pm: Yoga class	23 11am: Going to the beach with Tim 5pm: Clean the house	24 6:30 pm: Prep dinner for Megan 7:30pm: Dinner with Megan
25 4pm: Family arriving 5pm: Prep for dinner 7pm: Christmas dinner	26 9:30 am: Leave for Boxing Day shopping with Tim	27 7am: Put bins out 1:30 pm: Leave for yoga class 2pm: Yoga class	28 9:30 am: Leave for Spanish class 10am: Spanish class	29 1:30 pm: Leave for yoga class 2pm: Yoga class	30 2pm: Leave for Karaoke 3pm: Karaoke at the pub	31 5pm: Leave for new year's party at Dave's 6pm: Party at Dave's

Put the calendar up on the wall/fridge door where you can see it clearly. You are more likely to remember to look at it if you do so at the same time everyday, e.g., before breakfast, lunch and dinner.



Or you could use a diary. Make entries in the calendar for all important chores and appointments.

Make sure to always put a note for leaving the house an hour/half an hour before an appointment.

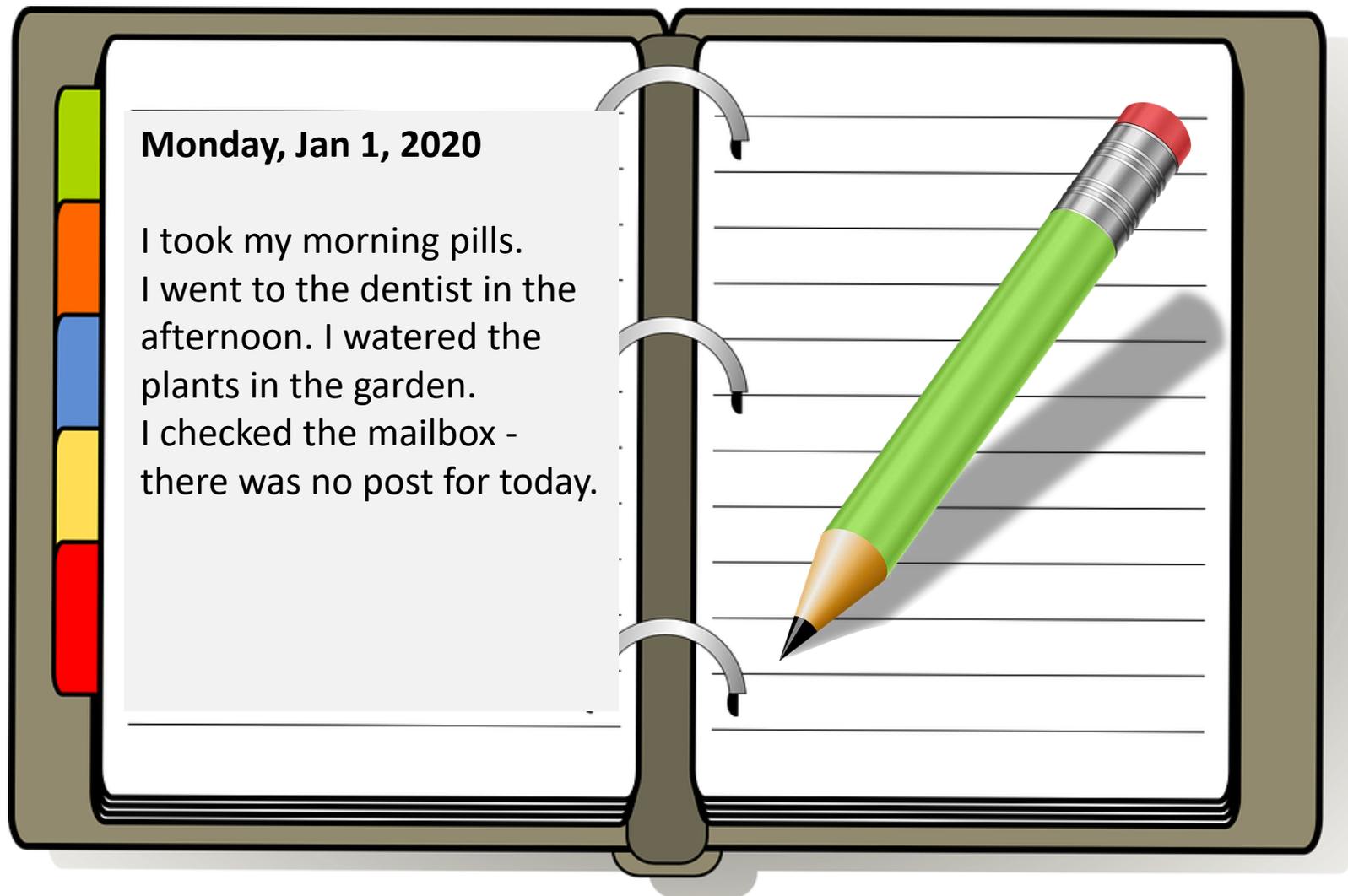
You can put a post-it note for yourself to check your agenda/calendar every morning. Put it on your cup of tea/coffee or television every night before sleep. Discard the note when you have done the task.



- 7am Put the garbage out
- 8am Take morning pills after breakfast
- 9am Make an appointment with the nurse
- 3pm Buy veggies for the dinner soup
- 6:30pm Make soup
- 8pm Check calendar and put messages on sticky notes on the coffee mug for tomorrow's chores
-

Create a to-do list for each day.
Tick off tasks when you have done them.

THINK IT. INK IT. REPEAT.



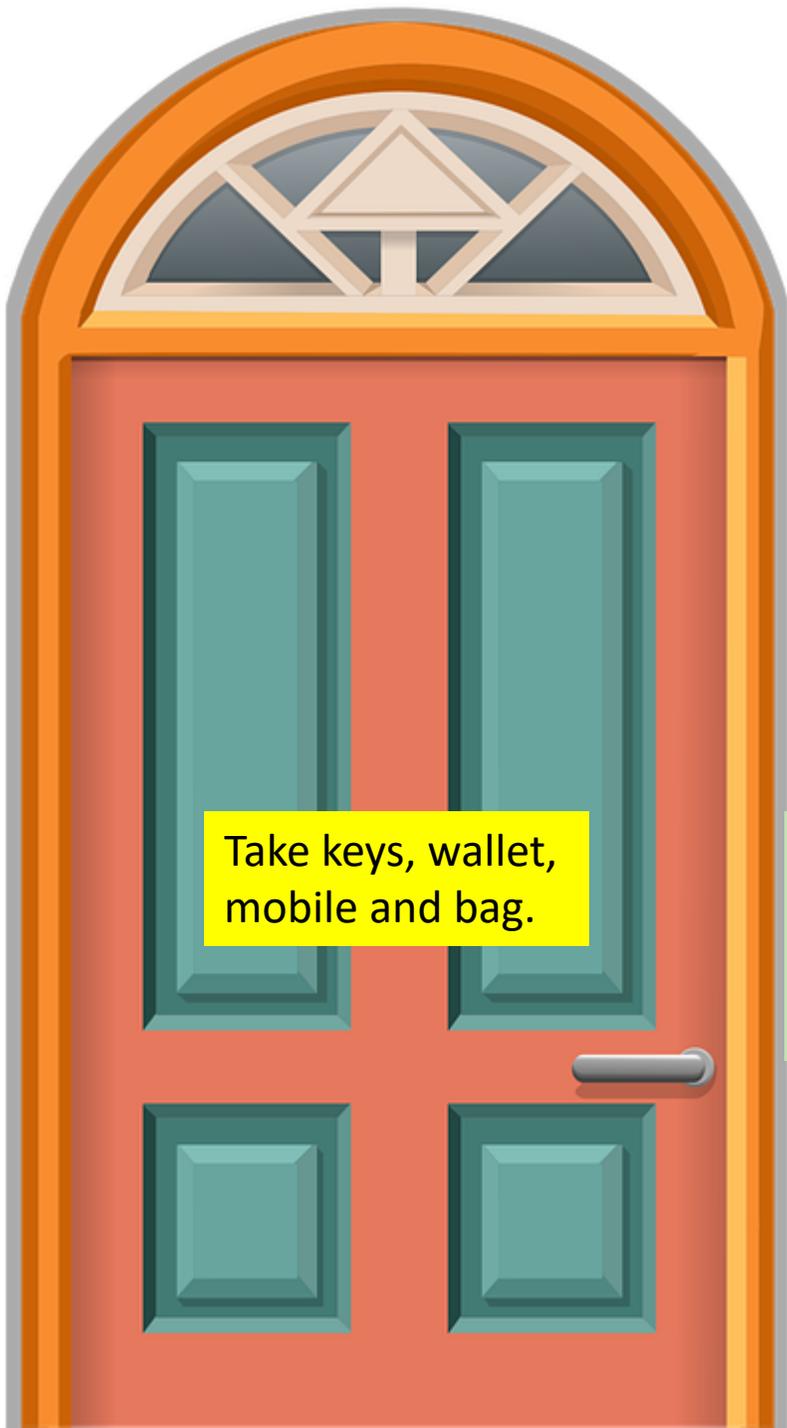
Write in your diary at the end of the day. You can write things you were able to do.

Make sure to keep your diary at one place!

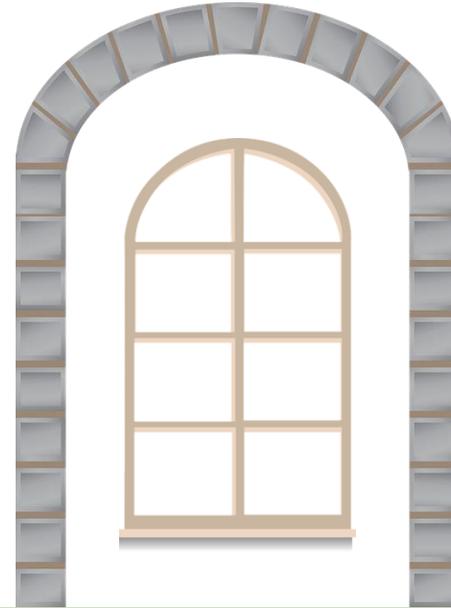
If writing is difficult, you could make voice recordings using a dictaphone or a smartphone app.

Keep a list of items that have run out at home.
Take it along when you go shopping. Cross
things off as you put them into your
basket/trolley.



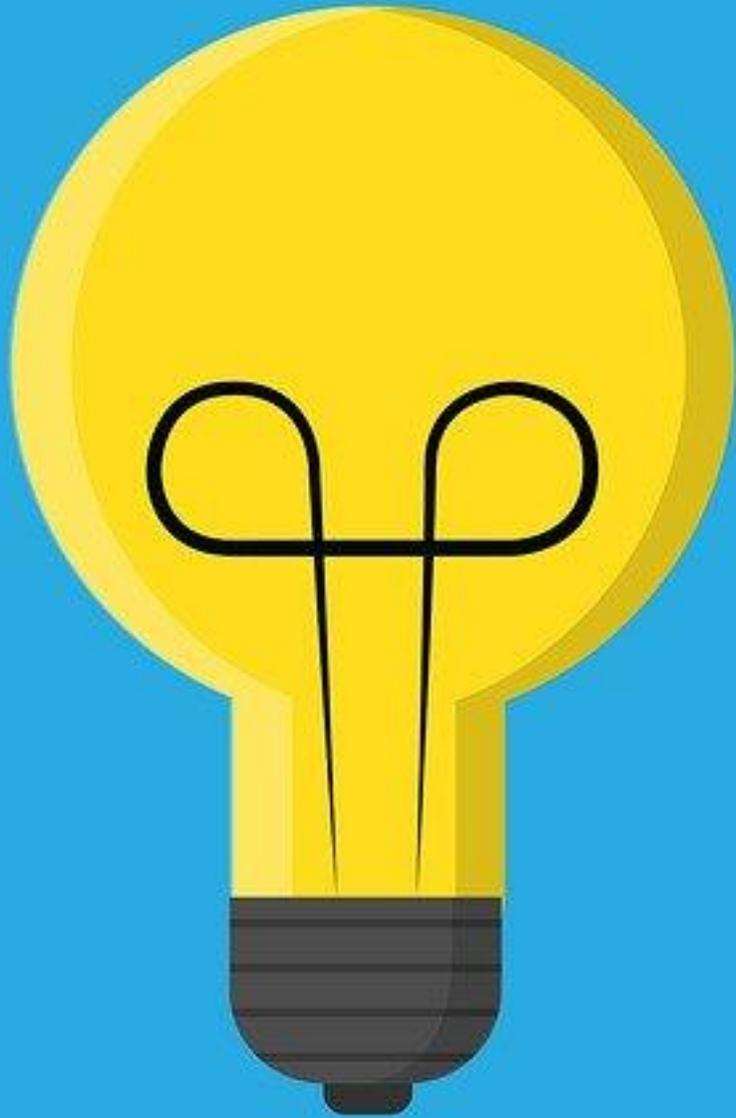


Take keys, wallet,
mobile and bag.

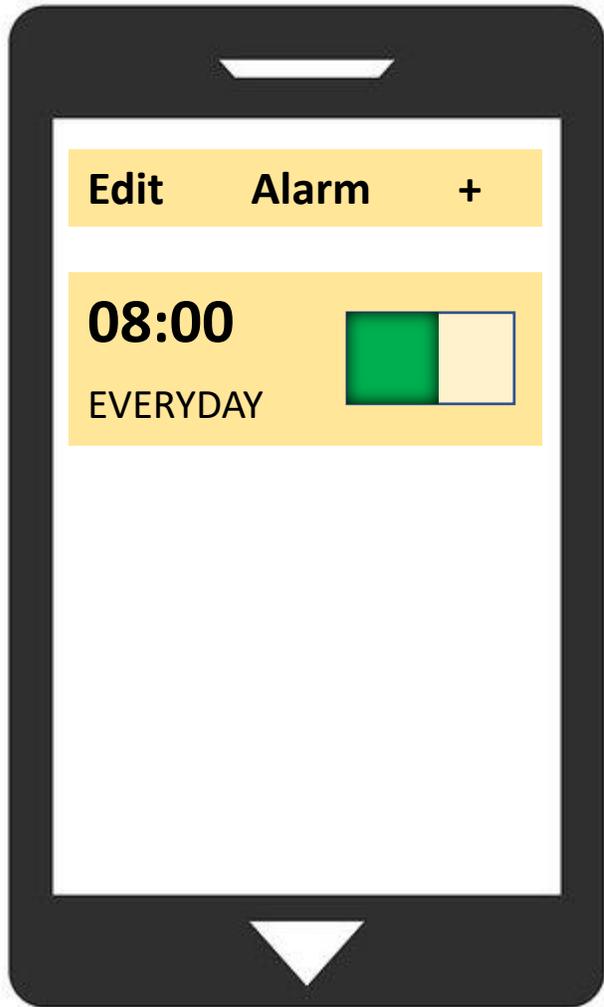


You can have a sheet/sign put up on front door (on the inside) to remind you to take your keys, purse, wallet or a shopping list with you when you go out.

**REMEMBER TO TURN OFF THE BURNERS
AND THE OVEN**



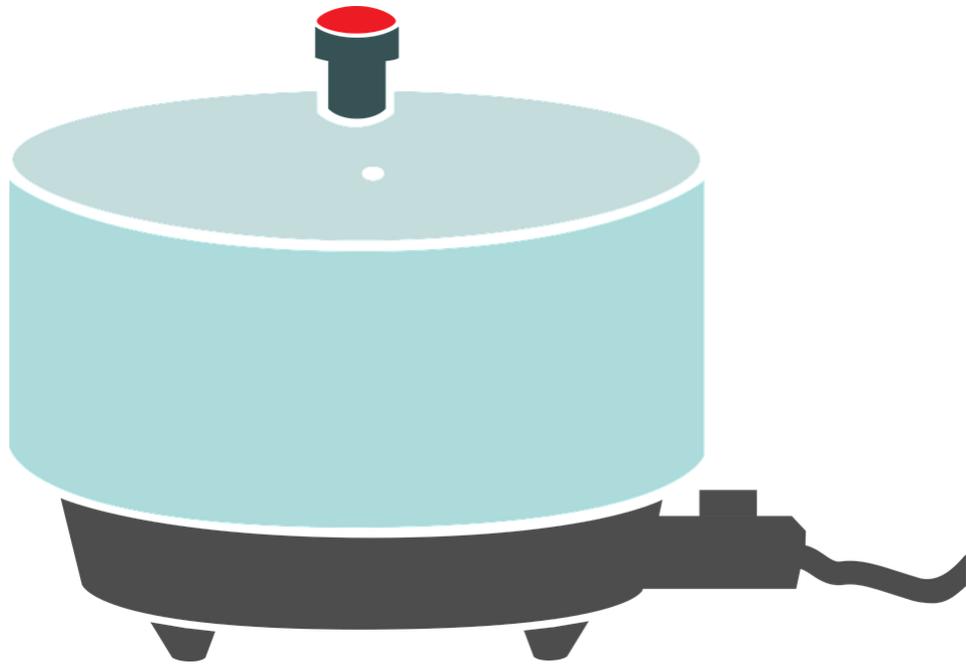
Having a small sign at the kitchen door/near the light switch is a good idea.



You can set an alarm on your phone to turn off the oven or the burner when cooking.

Setting alarms is a good idea to remind yourself when you have to leave for appointments or to complete important chores like taking medication on time.

Setting an alarm will help you know when the soup is done or when to take the cake out of the oven.



Write down why you have set the alarm, so you can get the task done when it rings!



Have you
taken your
pills?

*Can't
remember
why I came
into the
kitchen...*



Pay more attention before you set off for the kitchen/any other room in your house. Visualise the object that you want. For example, if you need to get a pair of cleaning gloves from the kitchen, repeat in your head as you go there, “gloves, gloves, gloves”.

Try not to stop to do other things on the way to the kitchen if possible as that might divert your attention.



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Strategies for Improving Planning & Organization





**As shown earlier, these tools
can help you plan things
effectively and stay
organized.**

**Diaries & calendars
Alarm clocks
Note books
White boards
Lists
Post-its
Smartphone apps**



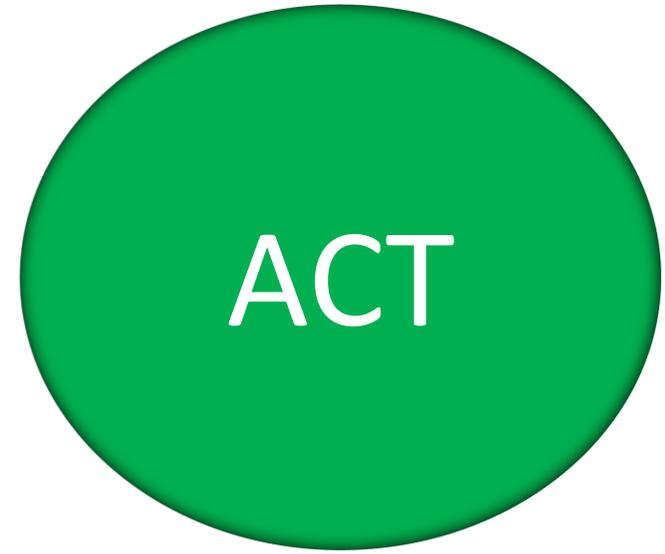
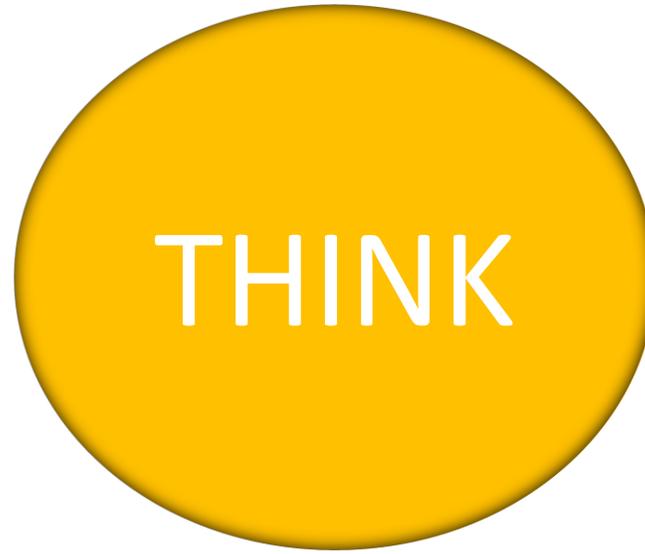
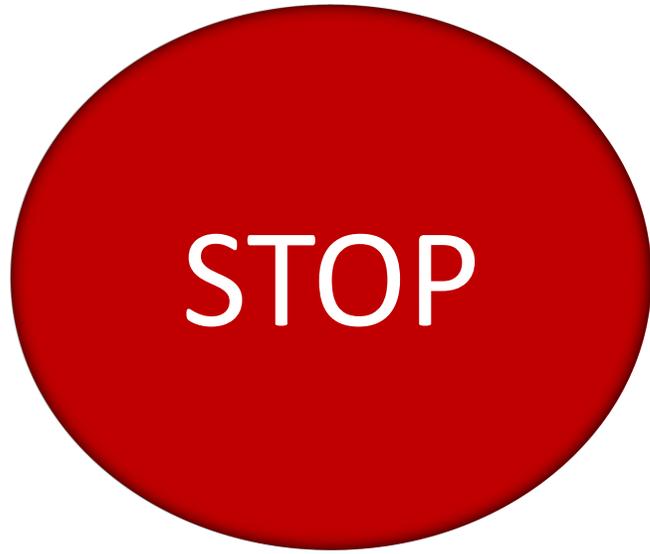
Try breaking down a complex task into simple sequential steps. Write the steps on sticky-backed notes or a notebook. Cross off each step when completed.

Decide on a consistent place to keep keys, glasses and wallets so it is easier for you to locate the items when you need them.

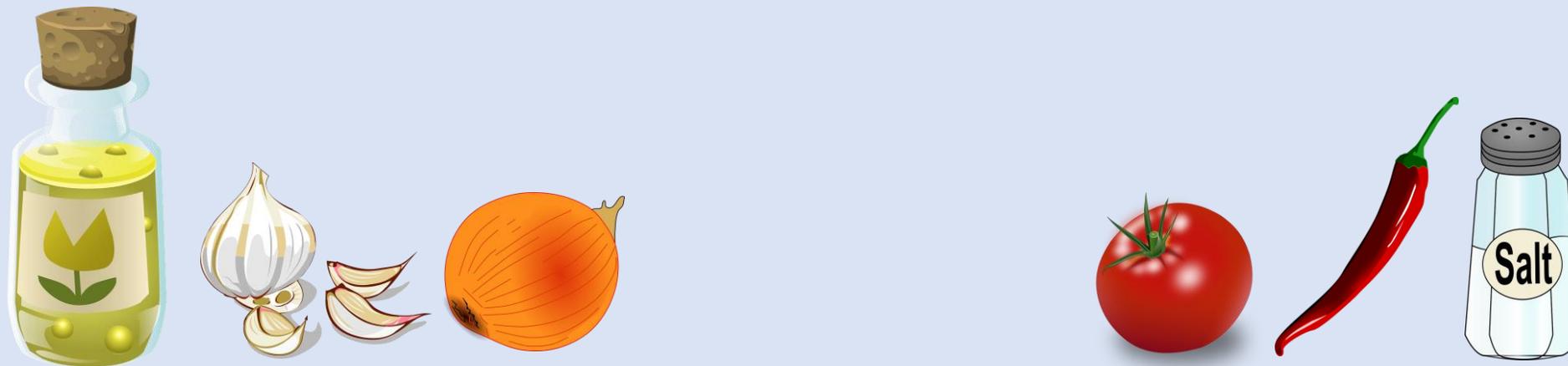




Simple pill trays with compartments for each day and time of day, can help keep you on track. You can speak to your pharmacist if you could have a pill box alarm system.



When making important decisions, write the options down and talk through them with someone if need be. It might also help to use visual prompts saying 'Stop-Think-Act' to help you with any impulsive decisions.



Line up your ingredients in order when making a meal.



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We have introduced many strategies in this book. Choose one or more strategies based on your cognitive difficulties and your preferences. Use them everyday.

To successfully adopt a new habit or a healthier lifestyle, it is important to set effective goals. People who set SMART goals, manage themselves better. Here are some tips that might help you set your own goals.

Setting Effective Goals





Tips for Making Effective Goals



Be clear on what you want to improve.

~~Health~~ → My diet

[Don't write "health" as it is too broad, instead choose a specific aspect; for example: my diet]



How are you going to meet your goal?

Be specific! And then be more specific!

Less fast food

Fewer snacks

One small bag of potato chips only once a week

Less alcohol



How will you know if you met your goal?

- Keep a record



What actions do you need to do to meet your goal?

- Clean out your cupboards of processed foods
- Re-learn to cook
 - Plan meals
- Go grocery shopping
 - Read labels



Be realistic.

- What can you achieve today?!
- What can you achieve in a week?!
- What can you achieve in a month?!



Give yourself room to grow.

- Start with your cupboards, **then** plan some meals, **then** learn to cook



Set the date! (between now and ...)

- By ____ (date) I will be eating freshly prepared meals at least 5 times a week.

Your goal should reflect what you need and want to do!

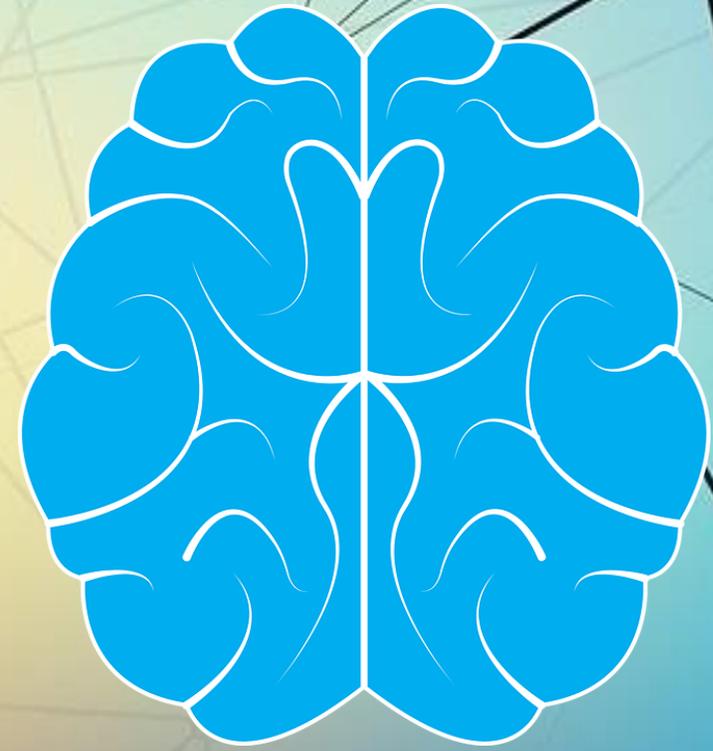
It should be to your benefit!



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Pillars of Brain Health

STOP SMOKING

Nicotine is a powerful drug that changes the brain as well as the body. While smoking may briefly boost mood and energy, this effect fades quickly, leaving smokers feeling tired, "down", and craving another cigarette. Smoking reduces how much oxygen gets to the brain, and increases the risk of brain damage from stroke.

It's never too late to stop smoking and enjoy the health benefits that will follow. After just two days of not smoking, brain function begins to improve and risk of stroke is reduced.

For tools to help you quit, visit:

The Canadian Cancer Society's website (www.smokershelpline.ca) or call their smokers' helpline toll free at 1-877 513-5333.

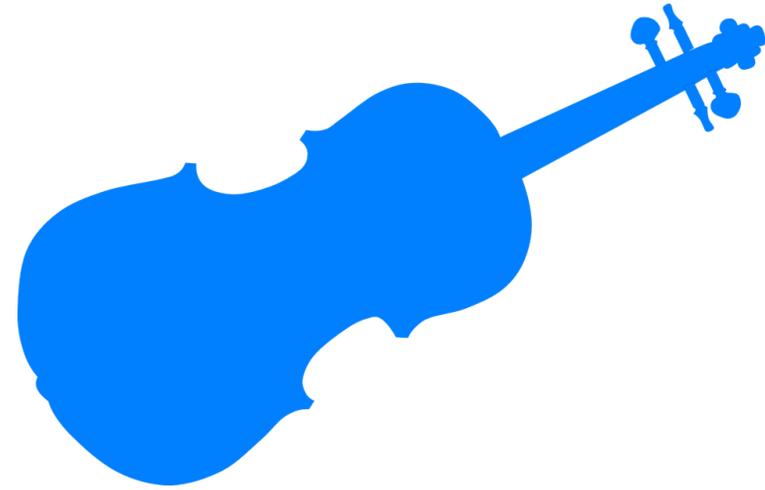


SOCIAL ENGAGEMENT

Keep in contact with your friends and relatives. Research shows that people who connect with friends or family in meaningful ways every day live longer and live better. Leave your computer and join a club, rally for a cause, volunteer, or take a walk with a friend.



CHALLENGE YOUR MIND



Do mentally challenging activities each day. Play cards or board games with friends. Nurture creativity through hobbies or crafts. Learn a new language or take up line dancing!

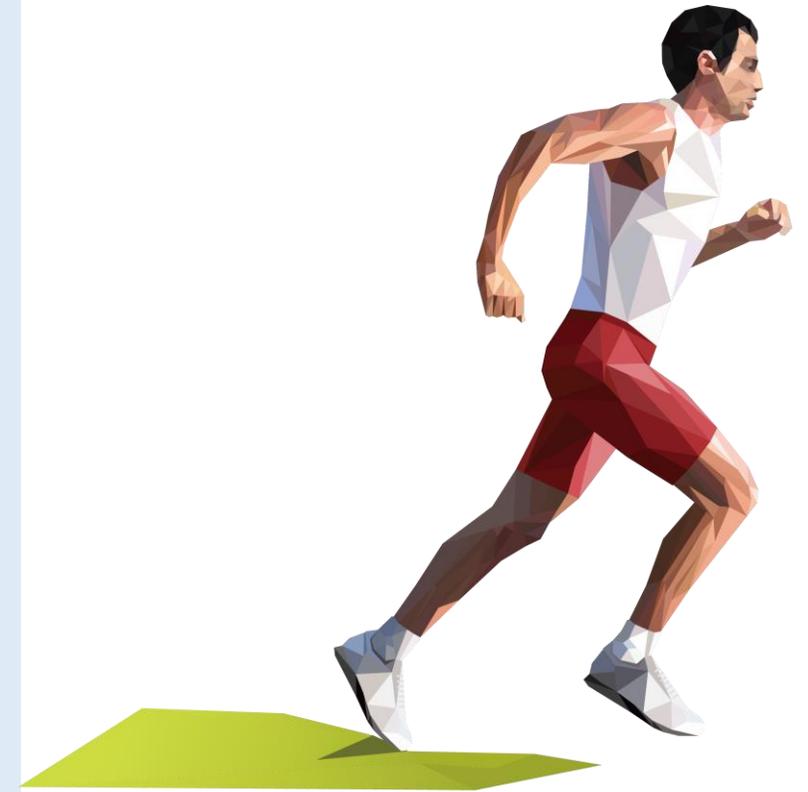
MOVE YOUR BODY

Brain health is directly tied to physical health. Exercise can help you think more clearly and may protect against cognitive decline.

You can improve your health with as little as 2.5 hours of moderate to vigorous activity each week. Play a sport, walk briskly, jog, swim or bike – even sessions as short as 10 minutes repeated through the week can make a big difference to your brain and body. Get stronger by adding exercises such as push-ups, leg squats and crunches two or three times a week. For ways to get active, visit:

<http://www.catie.ca/en/practical-guides/managing-your-health/4#exercise>

<https://www.canada.ca/en/public-health/services/being-active/physical-activity-your-health.html>



You can't eliminate stress, but you can learn to identify sources of stress and respond in healthier ways. Reduce your stress by setting realistic goals and managing your time effectively.

Deep breathing and other relaxation techniques, mindfulness meditation, and physical activity can help quiet the body and the mind. Yoga and other mind-body activities can promote mental and physical relaxation. Anxiety and depression will affect your memory and your ability to think clearly. Speak with your healthcare provider if you feel anxious or sad most of the time for two or more weeks. Effective treatments include regular physical activity, short-term talk therapy or medication.

To learn more about managing stress and negative moods, visit:

<http://www.catie.ca/en/practical-guides/emotional-wellness>

MANAGING STRESS & NEGATIVE MOODS

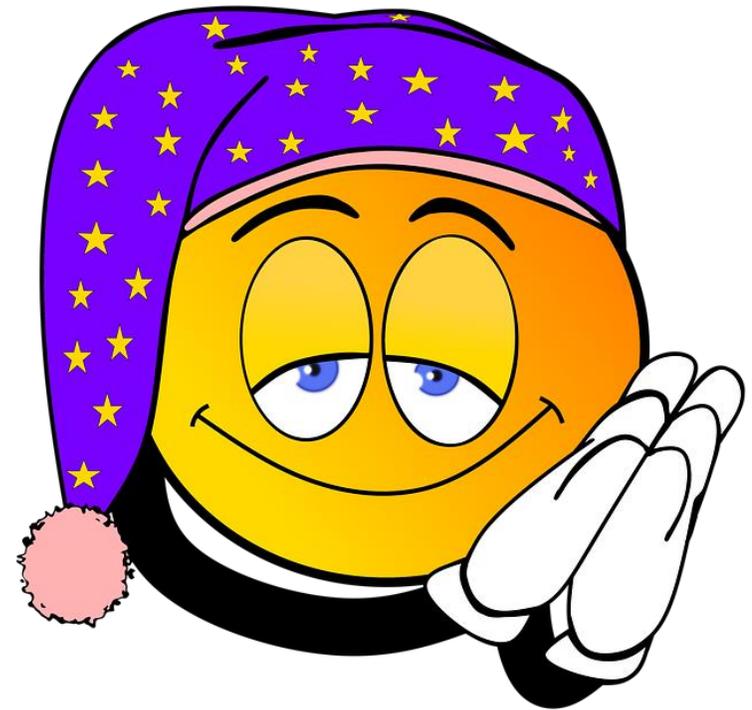


GET A GOOD NIGHT'S SLEEP

Your brain is very active during sleep. A good night's sleep helps improve memory and the ability to learn new information.

Develop a healthy sleep routine: Go to bed at the same time every night. Avoid naps during the day. Limit stimulants like coffee, cola and even chocolate, and avoid them entirely after 4 pm. Avoid large meals or strenuous exercise close to bedtime. Your brain is very active during sleep. A good night's sleep helps improve memory and the ability to learn new information.

Talk with your doctor if you have trouble falling asleep, wake too early in the morning, sleep too much for two weeks or more or if your sleep is chronically poor. Loud snoring may also be a sign of a more serious sleep disorder that may need treatment.



BRAIN DETOX

Many medications used to treat sleep problems, pain, or anxiety, including those available over-the-counter, can have negative effects on your memory and concentration. Review your medications with your physician. Limit your consumption of alcohol and recreational drugs.





Navigating Your Way Through the Handbook

Key Content

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We would like to hear what you think about this handbook. This will help us to understand its impact and make improvements as needed. Click on the link to complete a short survey:

<https://forms.gle/Bjuzbr5PMNpjr4qDA>

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